Genetically Exceptional?

Women's Experiences of Being At-Risk of Hereditary Breast and Ovarian Cancer.

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Abstract.

This thesis questions whether the experiences of women at-risk of hereditary breast and ovarian cancer (HBOC) might be genetically exceptional. Using a combination of retrospective in-depth interviews with women at-risk and observations of consultations carried out at a regional specialist centre, this research questions the genetic exceptionalism thesis and the argument that the experiences and decisions that women at-risk of HBOC make, are unique and thus different compared to those of women diagnosed with non-genetic, sporadically developing breast or ovarian cancer.

In examining the arguments for and against genetic exceptionalism, this thesis revisits the medical sociological literature on the doctor-patient relationship and discusses the difficulty in establishing who should be recognised to be the patient within the genetic consultation, the decision to undergo genetic testing and the decision to have risk-reducing, prophylactic surgery. The resulting analysis recognises the data to be moral accounts, constructed by research participants so that their utterances would be perceived in a particular manner. For example, while justifying their reported actions, participants were attempting to portray themselves as moral, responsible citizens, mothers, patients and women.

In addressing these four aspects of women's HBOC experiences, this thesis concludes that there is little unfamiliar to medical sociologists about the experiences described and the rationales given by the participants. Such data lends itself to the position where the notion of genetic exceptionalism cannot be supported. Consequently, the thesis concludes that the experiences of women at-risk of HBOC seem to be little different from other, non-genetic health experiences.

SECTION I: Literature Reviews.

Introduction.

1. Breast cancer medical literature.
2. Breast cancer sociological literature.
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Introduction.

We are standing on the threshold of a revolution in health care.

Dr John Reid, Secretary of State for Health, speaking at the launch of Our Inheritance, Our Future, June 2003.

We are increasingly led to believe that we are living through "the dawn of the genetic age" (Conrad and Gabe, 1999:505), that the promise of the Human Genome Project (HGP) is "alluring" (Zimmern, 1999:1282) and that genetic developments have occurred at an "explosive pace" (Garber, 1998:1639). From these descriptions, one could be forgiven for thinking that the current interest in the field of genetics is a new development. However, genetics has a lengthy history, which began long before the conception of the HGP.

The first study of inheritance was made by Gregor Mendel, an Austrian monk, in 1865 (Pilnick, 2002b). Whilst investigating inheritance patterns in pea plants, Mendel found three explanations for hereditary traits: autosomal dominant inheritance, autosomal recessive inheritance and sex-linked inheritance. The study of the genetics of inheritance was furthered in 1883, when Galton, a British scientist, coined the term 'eugenics', meaning "good in birth" (Pilnick, 2002b:27), to refer to "the science of improvement of the human race germplasm through better breeding" (Haller, 1963:3). The eugenics movement encouraged the practice of human reproductive hygiene, whereby individuals labelled as 'genetic defectives' had their plans for marriage, procreation and immigration controlled, whilst the 'genetically fit', usually members of the upper classes, were offered incentives to breed and "improve their genetic stock" (Conrad and Gabe, 1999:505).

'The new genetics' and the HGP.

The science of eugenics is today condemned as "absurd, simplistic or racist" (Conrad, 1997:143). In disassociating themselves from eugenic discrimination, advocates of 'the new genetics' go to great lengths to emphasise:

> the new genetics refers to knowledge and techniques arising out of the discovery of recombinant DNA in the 1970s. It involves research into the genetic components of disorders…and the clinical application of genetic knowledge to testing, screening, informing and treating affected people.
>
> Alderson et al, 2001:3.

This latest period of genetic development has been termed microeugenic (Katz Rothman, 1998). Unlike macroeugenics, which focused upon the separation of diverse human gene pools on the basis of race and religion, microeugenics concentrates upon the genetics of disease. Its aim is to eliminate or prevent certain diseases. This form of genetics is still politically sensitive as decisions have to be taken regarding which diseases are serious enough to warrant intervention to aid their elimination (Katz Rothman, 1998). The first use of microeugenics saw pregnancy and childbirth come under focus (Stacey, 1998). Foetuses were screened for Tay Sachs and sickle cell anaemia, and if the foetus was found to be 'defective', women were offered abortions.

The HGP was launched in 1990 by the U.S. Department of Energy and the National Institutes of Health. Described as "a search for the holy grail, investigating the essence of human life, and decoding the book of life" (Conrad and Gabe, 1999:506), the goals of the HGP were to:

1) Identify all the genes in human DNA,
2) Determine the sequences of the three billion chemical base pairs that make up human DNA,
3) Store this information in databases,
4) Improve tools for data analysis,
5) Transfer related technologies to the private sector, and,
6) Address the ethical, legal, and social issues that may emerge from the project.

It was initially thought that mapping the human genome would take 15 years to complete. However, only 50 years after Crick and Watson's successful sequencing of the structure of DNA, the genome was drafted in April 2003 (Human Genome Project Information, 2004), two years ahead of schedule.

Prior to the commencement of the HGP, the human body was estimated to have between 60,000 and 100,000 genes (Pembury, 1998; Ridley, 1999). However, once the genome had been sequenced, just 30,000 genes were found. Consequently, one might think that the human genome is not as complex as once believed. For example, the genomes of less sophisticated animals, such as the fruit fly and the chimpanzee contain a similar number of genes to that found in the human body (Rose, 2004). Nevertheless, a different reading would see that the human genome is more complex than originally thought. Given the limited number of genes located, it is likely that genes interact with one another rather than acting in isolation. It is the DNA found in these genes that allows scientists access to the genetic basis of human life, and offers a means of investigating one's destiny, as revealed in our genes.

Developments in the HGP enabled speculation about the future of health care to be made. Potential treatments including the introduction of gene therapy, in which the composition of cells can be manipulated to eliminate certain diseases and conditions, and pharmacogenetics, a form of 'bespoke medicine' (Radford, 2003) in which medication would designed specifically to target an individual's genetic profile, were given credence. Yet little of this initial promise has been put into practice. Marteau and Richards argued, "one of the main driving forces behind the research [the HGP], is to develop therapies; as yet, however, very few are available" (1998:xiii), whilst Shakespeare rightly pointed out that "the new genetics currently promises more that it can deliver" (1998:666). This has led to the criticism that the potential of genetics has been 'over-hyped' (Zimmern, 1999; Cardon and Watkins, 2000; Holtzman and Marteau, 2000).

One possible 'success', however, is the availability of pre-symptomatic genetic testing, in which genes that signal a pre-disposition towards certain diseases can be identified. Consequently, Olopade (1997) described how the HGP promised tools for the early identification of heightened risk, so that carriers of mutations could benefit from screening and preventative measures. Hereditary breast and ovarian cancer (HBOC) is one such disease.

The HGP and breast cancer.

In September 1994, the first gene found to signal a pre-disposition of HBOC, termed BRCA1 (BReast CAncer 1) was sequenced. The discovery of a second breast cancer gene, BRCA2, followed in December 1995 (de Vries-Kragt, 1998; Parthasarathy, 2001). Locating BRCA1 and BRCA2 allowed a different explanation of disease causation to be offered:

> cancer is no longer a disease of the organs and guts, a disease of the flesh of the body. Cancer is a disease of the cell, of the program of the body, a genetic disease.
>
> Katz Rothman, 1998:135.

As I discuss later, searching for a mutated gene is not a straightforward task. Genetic testing involves a blood sample being collected from a known carrier, or if this is unattainable, from a person diagnosed with breast or ovarian cancer. This sample is examined, and attention is paid to the presence (or lack) of genetic mutations on just two chromosomes: chromosome 17 for BRCA1 mutations and chromosome 13 for BRCA2 mutations.

Breast cancer, genetics and the National Health Service.

In September 2000, a few weeks before I commenced my doctoral research, the Government published the NHS Cancer Plan (NHS, 2000). In this document, the Government outlined their aims for future NHS cancer care:

> to save more lives, ensure people with cancer get the right professional support and care, as well as the best treatments, tackle the inequalities in health that mean unskilled workers are twice as likely to die from cancer as professionals, build for the future through investment in the cancer workforce, through strong research and through preparation for the genetics revolution, so that the NHS never falls behind in cancer care again.
>
> NHS Cancer Plan, 2000:5.

Despite the promise to "build for the future….[and prepare] for the genetics revolution, so that the NHS never falls behind in cancer care again", the NHS had already effectively failed to meet its aims. By the time the Cancer Plan was published,

scientific developments had already enabled women at-risk of HBOC to be offered genetic testing[1]. Such testing has been available in the UK since the late 1990s, and was thus "already a reality" (Olopade, 1997:209). The NHS did not so much need to prepare for the genetics revolution, but respond to it and quickly create an infrastructure that could cope with the challenges that widespread genetic testing would inevitably create.

However, it took some three years after the NHS Cancer Plan was published for the Genetics White Paper to arrive (Department of Health, 2003). The White Paper promised that with an increasing number of genes linked to the onset and causation of disease, the NHS would be able to:

> target and tailor treatment better to offset their impact and even to avoid the onset of ill-health for years in advance.
>
> Department of Health, 2003:1.

The discovery of BRCA1 and BRCA2 has enabled the fight against breast cancer to intensify. Breast cancer is the second biggest killer of women worldwide. In 1997, Olopade estimated that in the year 2000, one and a half million women worldwide would die from the disease. Statistics show that over two million women died from breast cancer in 2000, and just fewer than 34,000 English women were diagnosed with the disease (NHS, 2004a).

Hopwood (1997) conjectured that 13,500 British women, between 25 and 60 years of age, might be at-risk of developing HBOC. Currently, there are 18 regional genetics specialist centres in the UK (Department of Health, 2003), each serving a population of between two to six million people (Donnai and Elles, 2001). Given this limited infrastructure, provision is currently stretched and it is possible that the needs of women identified as being at-risk of HBOC are not being adequately addressed. Moreover, as greater numbers of the public become aware of genetic testing, these services will only come under more pressure.

[1] Men can also be at-risk of HBOC and carry a mutated gene. Yet throughout this thesis, I have routinely used the term 'women' to discuss people at-risk of HBOC. I have made this decision consciously, as the data I discuss is derived from interviews and consultation observations that only featured female patients.

Referral to one of the specialist genetics centres is dependent upon many factors. At a personal level, referral is dependent upon individuals' knowledge of the service, and awareness that they have a heightened risk of developing HBOC. At a structural level, referral is dependent upon the individual's GP being aware of and willing to make a referral to a Family History Clinic, and the availability of service.

Some women have had to wait up to 18 months for referral to a Family History Clinic (Campbell, 2003), and of the women I interviewed some travelled 60 miles for their appointment. Once a woman has been referred and undergone testing, it can take up to a year to receive the result of a genetic test. Under new Government plans however, results should be expected within two weeks when the mutation to be searched for is known and eight weeks for an unknown mutation.

The research question.

> When a new genetic association, like the association between BRCA1 mutations and breast cancer, spins off of the whirlwind of genomic research into the calm pond of clinical practice, its impact produces a wide series of ethical and social ripples.
>
> Juengst, 1998:189.

The promises made by the Government and outlined in the recent genetics White Paper (2003) will in all probability lead to ever-greater numbers of women reacting to their risk of HBOC, and seeking a referral to one of the regional specialist testing centres. Consequently, there is a pressing need for the scientific community to investigate the ethical and social ripples that Juengst (1998) described. Whilst scientific and social scientific research has examined women's use of genetic testing since the mid 1990s, these have tended to focus upon factors such as the levels of anxiety or depression experienced following an individual's awareness of their increased risk (Thirlaway et al, 1996; Lodder et al, 2001), the patient's informational needs (Hallowell et al, 1997; Beaver et al, 1999) and their perception of their risk (Bluman et al, 1999; Cull et al, 1999). However, much of this research argued that whilst rapid scientific discoveries were made, understanding of the social consequences of the HGP has lagged behind (Willis, 1998). Van Zuuren argued, "advances in clinical genetics are far ahead of people's moral and ethical readiness to deal with the dilemmas created" (1997:70),

while Hallowell (2000) echoed these concerns, pointing to the social, legal and ethical ramifications that genetic knowledge may have for its recipients. Therefore, although "technology in the field of genetics and genomics has advanced so rapidly in recent years….we are still low on the learning curve in terms of translating molecular genetic knowledge into patient care" (Anon, 2001:325).

In light of such comments, the research question that I address in this thesis engages with these issues and examines women's experience of being at-risk of HBOC. The research question posed is: **are women's experiences of being at-risk of HBOC genetically exceptional?**

The research question challenges advocates of the genetic exceptionalism thesis, who consider that the experience of a genetic related disease is qualitatively different from its non-genetic counterpart. However, whilst comparing the histology of a hereditary breast cancer with that of a sporadically developing breast cancer, Garber (1998) found no difference other than genetic breast cancer being a more aggressive type. Thus, it seems possible that the experience of women at-risk may not be as diverse as those experienced by breast cancer patients as might have been envisaged. The specific experience of being at-risk of HBOC may not therefore not exceptional.

The research question is timely in that it examines women's experiences of being at-risk of HBOC, when the provision of genetic services in the UK is expanding and it is likely that greater numbers of women will face a similar experience to that I discuss. Moreover, greater emphasis is being placed upon the influence, or effect of our genes. Whilst once the scientific community considered that the stars determined our fate, contemporary thinking now sees that genes have replaced stars as a determining factor (Conrad and Gabe, 1999).

Structure of the thesis.

In engaging with the research question, the thesis is structured into eight chapters.

Section I.

In the opening three chapters, I review the existing literature within three, diverse fields that inform the research. Following this, I address the methods and methodology utilised whilst conducting the research.

In chapter one, "A Medical Review of the History of Breast Cancer", I examine the way that breast cancer has historically been perceived and treated, from the developments in the Hippocratic era of medicine, through to the current practice of investigating genetic risk of the disease and where surgery is carried out prophylactically.

In chapter two, "The Psychosocial Impact of Hereditary Breast and Ovarian Cancer", I review the existing literature in relation to the decision to undergo prophylactic mastectomy and oophorectomy in order to reduce one's risk of developing HBOC. In doing so, I draw upon women's cancer-related worries and anxieties, as well as women's perceptions of their femininity, sexuality and body-image following surgery. Although recognising that the success that the existing literature has had in drawing attention to important considerations for women at-risk, I am critical of the methodologies that have been evoked.

In chapter three, "The Sociology of the Doctor-Patient Relationship", I review some of the medical sociological literature that has examined the doctor-patient relationship. I illustrate how the doctor-patient relationship has been conceived, and then review three of the most popular models of doctor-patient interaction in relation to their decision-making characteristics: the disease-centred model, the widely advocated patient-centred model, and the doctor-patient relationship as a site for collaboration.

In chapter four, "Methods and Methodology", I discuss the stance adapted during the research, and provide a detailed account of the methods utilised to collect and analyse the data.

Section II.

Section two of the thesis draws upon my own research data. However, prior to this, I offer a concise summary of the genetic exceptionalism in order to contextualise the following four data chapters.

My research question asks whether women's experiences of being at-risk of HBOC may be considered as genetically exceptional. Advocates of the genetic exceptionalism thesis consider that genetic medical information is somehow unique compared to other, non-genetic medical information. Therefore, as an introduction to the data chapters, each of which address a distinct phase of the HBOC experience, I summarise the arguments for and against genetic exceptionalism.

In chapter five, "Who is the Patient?", I examine the difficulty in determining a sole inhabitant of the 'patient' role within the genetics consultation. This stems from a growing recognition that genetic investigation implicates more than just one person (Richards, 1993). Examining one consultation in-depth, and using an approach informed by conversation analysis, I illustrate how interactionally, more than one person can be considered to be the patient. Following this, I discuss whether the presence of more than one person in the genetics consultation might be considered to be an example of genetic exceptionalism.

In chapter six, "The Doctor-Patient Relationship", I continue the focus upon doctor-patient interaction initiated in chapter five. In this chapter, the emphasis is placed upon the type of interaction that occurred in the consultations. Building upon the foundations laid in chapter three, I examine the data in light of the three of the most prominent and encompassing models of doctor-patient interaction within the medical sociological literature: the disease centred model of doctor-patient interaction, the patient centred model of doctor-patient interaction and the collaborative model of doctor-patient interaction. In addressing these models, I propose that a consultation, rather than being characterised in terms of just one of these typifications, can contain many elements of each of them. I argue that doctor-patient interaction should be able to react to the requirements of each patient, rather than being rigidly structured as an example of one

particular model. Furthermore, I discuss how this should be extended to all medical consultations and therefore argue against the genetic exceptionalism thesis.

In chapter seven, “Genetic Testing Decisions”, I investigate the rationales that women provided to explain their decisions to seek and decline genetic testing. As I have already discussed, advocates of the genetic exceptionalism thesis argue that genetic material is unique. I challenge this theory, questioning whether the justifications women gave for their decision to seek genetic testing are indeed exceptional and thus are dissimilar from justifications given for other health related decisions.

In chapter eight, “Surgical Decisions”, I reach the final part of my investigation of women’s HBOC experience. In this chapter, I discuss the accounts that women gave regarding their decision whether or not to undergo risk-reducing, prophylactic surgery. Again, the justifications and rationales for their decisions are examined, and assessed in relation to the genetic exceptionalism thesis. I also examine the impact that surgery can have upon women’s perceptions of their body-image, femininity and sexuality, and discuss this in terms of the genetic exceptionalism thesis.

I conclude the investigation of women’s experiences of being at-risk of HBOC by returning to the genetic exceptionalism thesis. I respond to the claims made by protagonists of the debate in light of the discussion made in the four data chapters. I assess whether the genetic exceptionalism thesis can adequately account for women’s experiences of being at-risk of HBOC, and in turn, whether the accounts given by the women demonstrate that a revolution in health care has occurred. I conclude the thesis by making tentative recommendations for future policy and cancer care provision in light of my results and analysis, and suggest possible lines of future enquiry.

The thesis now places women’s experiences of being at-risk of HBOC in its historical context by reviewing the medical history of breast cancer, beginning with ancient Egyptian treatments, before discussing the introduction of surgical techniques and contemporary challenges initiated by genetic medicine.

Chapter One. A Medical History of Breast Cancer.

> A chance to cut is a chance to cure.
>
> Lerner, 2001b:78.

The aim of this literature review is two-fold. Firstly, I address the medical literature on the history of breast and ovarian cancer. This review is only intended to be a very brief résumé of the history of breast cancer, and it is appreciated that large periods of history have been omitted. However, I discuss the influential issues in the development of the history of breast cancer that are significant for this study. Secondly, I focus upon the 'genetics revolution' and how this has affected both our current understanding and perceptions of breast and ovarian cancer, and how they are treated once a pathology is found and the disease diagnosed. I also discuss the prophylactic management of breast and ovarian cancer.

In summarising the history of breast cancer and development of its treatments, the aim of this chapter is to illustrate that breast cancer is not a new affliction, and therefore that contemporary medical understanding and reactions towards the disease need to be contextualised.

1.1. Breast cancer: 3000-2500 BC.

The earliest surviving reports of breast cancer, found in the 'Edwin Smith' papyrus[2] originating from the Egyptian era describe, "bulging tumours of the breast" (Peters, 1999:389). Outlining the treatment for cancer, the manuscript stated:

> thou shouldst bind it with fresh meat the first day; thou shouldst treat it afterward with grease, honey [and] lint everyday.
>
> Egyptian Orthopaedic Association, 2002.

[2] The papyrus was named after the Egyptologist Edwin Smith, who purchased the manuscript during the 19th century.

At this time, the only available surgical option involved the cauterisation of the tumour. Cautery describes the practice whereby flesh is cut away or burnt using heated apparatus or chemicals. Whilst still practised in a limited capacity, the greatest use of cautery occurred prior to the introduction of professionalised surgery, anaesthesia and antisepsis in the 19th century (The Chemical Heritage Foundation, 2001).

1.2. Breast cancer: 525 BC – 848 AD.

During the Hippocratic era of medicine (525 BC–848 AD), disease was perceived to be organic and physiological. The Hippocratic writers[3] are reported to have coined the term cancer to describe the "hard, spiny cancerous tumours" believed to resemble crabs[4] (The Chemical Heritage Foundation, 2001). Towards the end of the era, the Greek physician Galen (131-200 AD), influenced by Hippocratic theories, developed the disease framework of humoral medicine. Galen considered that an excess in one or more or the four humors, blood, phlegm, yellow bile and black bile, created "a general state of disequilibrium" (Lindemann, 1999:9). Diseases such as cancer were considered to be a symptom of a broader dysfunction.

According to Lerner (2002), breast cancer was treated by purging, bleeding or a special diet; de Moulin suggested that one such diet incorporated:

> [a] sieved barley infusion and milk whey in particular; malva, atriplex and pumpkin are recommended as vegetables.
>
> de Moulin, 1983:8.

However, historical evidence suggests that an early form of mastectomy was also carried out. Reports describing the surgical removal of the breast originate from the 1st century (AD). Leonides, a surgeon who performed the procedure, described his actions in the following manner:

[3] It is unclear which manuscripts the figure 'Hippocrates' wrote; therefore, when writing about the era, it is usual to refer to the 'Hippocratic writers' (Lindemann, 1999; Boylan, 2002).
[4] The term 'cancer' is a derivative of the Greek words karkinos / karkinoma, meaning crab.

> I make the patient lie on her back. Then I make an incision into the sound part of the breast above the cancer and I apply cauteries until an eschar is produced that stops the bleeding. I then make another incision and cut into the deep of the breast and again sear the severed parts. This I repeat often, alternatively cutting and burning in order to arrest the bleeding. For in this way the danger of haemorrhage is avoided. When the amputation is completed, I burn once again all parts until they are dry.
>
> Leonides, cited in de Moulin, 1983:5-6.

The following image, an etching by Dutch artist de Hooghe, depicts such a procedure.

Figure one: De Hooghe's portrayal of the mastectomy.

Source: de Moulin, 1983:28.

The Hippocratic and Galenic principles of medicine remained popular until the 15th century (Lindemann, 1999). Throughout the Renaissance, debates regarding the most appropriate manner in which to treat breast cancer continued. The French surgeon Paré (1510-1590) recommended that surgery only be carried out if the entire tumour could be removed (Mediweb, 2002), whilst Vesalius (1514-1564), a Flemish anatomist and surgeon, endorsed the use of vascular ligatures in place of cauterisation (Breast Cancer Society of Canada, 2002; New Advent, 2002). Another popular treatment for breast cancer was to treat the area with pastes made from arsenic (National Institute of Health,

2002), which de Moulin suggested consisted "of the juice of strychnos [nightshade] or of pompholyx [impure oxide of zinc]" (1983:8).

1.3. Breast cancer: 17th century.

In the course of the 17th century, breast cancer treatment similar to that which we see today, began to be practised albeit in a limited capacity. Physical examinations of the breast were performed, paying attention to: the affected breast and immediate environment, the colour of the skin, the presence or absence of swollen veins, the position of the nipple, the consistency of the tumour, any potential skin irregularities, whether the tumour was attached only to the skin or to the axilla, and whether the lymph nodes were palpable in the armpit, superclavicular area and neck (de Moulin, 1983).

Total mastectomies were carried out (National Institute of Health, 2002) although subsequent advances in anaesthesia and developments in surgical techniques would lead to greater levels of post-surgical survival, and the procedure would become far more popular some years later. Lymph nodes were routinely removed during surgery following Le Dran's (1685-1770) recognition that cancer could spread to the axillary or lymphatic system, and would worsened the patient's prognosis (The Chemical Heritage Foundation, 2001). Such a practice continues today.

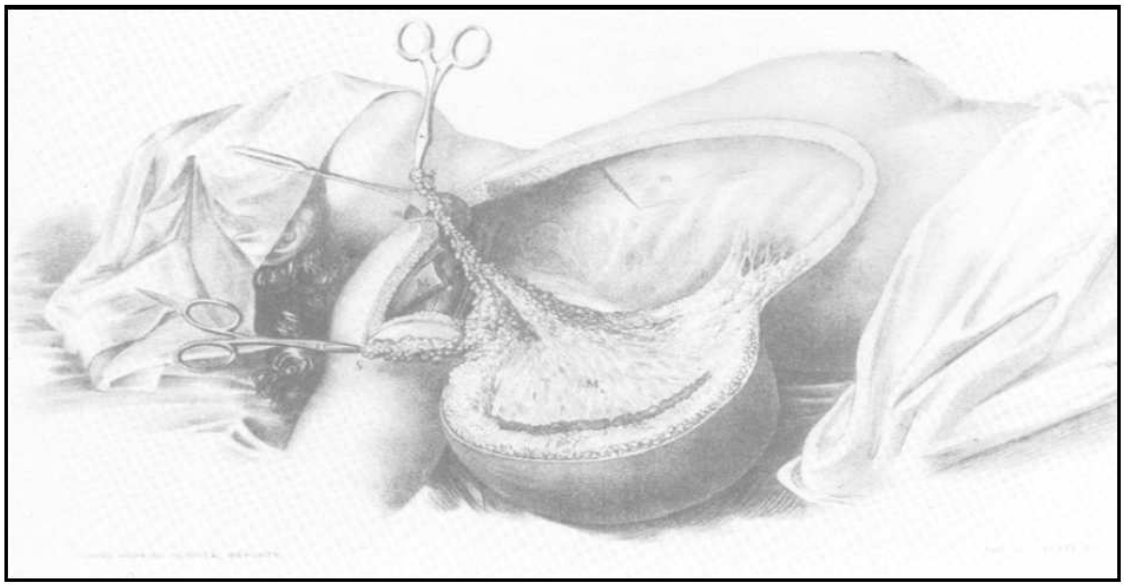
1.4. The Halstead radical mastectomy and the oophorectomy.

In the 19th century, an important advance in the treatment of breast cancer arose with the work of the American surgeon, Halstead (1852-1922). According to Lerner (2002), Halstead popularised the radical mastectomy[5], although elsewhere, he suggested that it was not an innovative procedure, but built upon existing surgical techniques (Lerner, 2001b). Halstead's radical mastectomy entailed removing the diseased tissue and flesh around the cancerous site, excising the pectoral muscle and performing an axillary dissection, through a wide skin excision of the breast.

The following illustration depicts the extent of the Halstead radical mastectomy.

[5] The procedure was subsequently known as the 'Halstead radical mastectomy'.

Figure two: The Halstead radical mastectomy.



Source: de Moulin, 1983:84.

Whilst Lerner (1998) described the Halstead radical mastectomy as "extensive and disfiguring", it was considered to provide the best opportunity for the patient to be cured:

> Halstead believed that a careful, meticulous operation that removed the breasts, axillary nodes and the chest wall muscle…potentially removed all cancerous cells and could thus produce 'a cure of cancer of the breast'.
>
> Lerner, 2002:30.

Between the 1880s and the 1950s, the Halstead radical mastectomy became established as the preferred way of surgically treating breast cancer in British and American operating theatres (Lerner, 2001b). However, a further development arose with the recognition that the growth of a tumour could be controlled. Whilst observing lactating sheep during the late 1880s, Beatson theorised that a decrease in hormone production would reduce the risk of developing breast cancer (Smith, 1997). In 1886, Beatson was the first surgeon reported to have carried out an oophorectomy in a woman diagnosed with breast cancer (Stewart, 1997). Today it is still believed that removal of the ovaries reduces the threat of developing breast cancer. The ovaries produce the hormones oestrogen and progesterone, and oestrogen especially, is implicated in the development

of breast cancer. Hence, if the ovaries are removed, then hormone production is ceased, and one important risk factor for developing breast cancer is eliminated. Consequently, Beatson was credited with the introduction of hormonal, or endocrine therapy for breast cancer.

1.5. Chemotherapy.

A further development, which would later be used in the fight against cancer, was the discovery of chemotherapy. The German chemist Ehrlich (1854-1915):

> envisioned the creation of 'magic bullets' compounds that would have a specific attraction to disease-causing micro-organisms.
>
> The Chemical Heritage Foundation, 2001.

These 'magic bullets' destroyed the micro-organisms that caused disease, but would not damage other micro-organisms existing in the body. Chemotherapy sought to only destroy the cells that caused disease.

By 1958, the first patient oncology chemotherapy trials had taken place using the drug 'Thio-tepa'[6] (Peters, 1999; Lerner, 2001a). The trials concluded that chemotherapy could delay any recurrence of the cancer (Lerner, 2001b), as the treatment attacked DNA and interfered with the normal pattern of cell replication (BMA/RPSGB, 1997).

The potential benefit that chemotherapy gave in terms of fighting cancer led it to be hailed as a wonder treatment (National Institute of Health, 2002). By the 1970s, approximately 30 different cancers could be treated with chemotherapy. Endocrine therapy developed, and the drug 'Nolvadex', later to be known in its generic form, tamoxifen, was licensed by the Committee on the Safety of Medicines in 1973. It was later licensed as an adjunct therapy for breast cancer. According to Powles, "results were encouraging, showing a significant reduction in the risk of relapse and death" (1997:255). Today, over 50 drugs are used, both alone and in combination with others, to aid the recovery of cancer patients (Cancer Backup, 2004).

[6] Thio-tepa is still used today to treat bladder and breast cancers (BMA/RPSGB, 1997).

1.6. Family history.

Broca, a French surgeon and anthropologist (1824-1880), theorised that breast cancer ran in families as early as 1866 (Bennett et al, 1998). However, it was Crick and Watson's discovery of the structure of DNA in 1953 that allowed a molecular level understanding of health and disease to develop (The Chemical Heritage Foundation, 2001). Over time, Crick and Watson's work was extended and DNA came to be understood as "the basic stuff of heredity" (Elmer-Dewitt, 1994:32). This enabled scientists to postulate about familial patterns of disease and inheritance. Specifically, DNA sequencing of individual genes allowed scientists to determine if there was any genetic explanation that could account for the development of certain cancers. At first this led to the discovery that certain genes could act as tumour suppressors (Mueller and Young, 1998). However, further investigation showed that if the genes became mutated, malignant disease could develop.

The greatest potential for development in the understanding of genetics and disease was offered with the Human Genome Project. The idea of mapping the human genome was initiated in 1969 by McKusick (Mueller and Young, 1998), although the greatest progress was made following the support and significant sponsorship given to the study by the American Government in 1984. In 1990, the Human Genome Project was officially launched (Pilnick, 2002b).

The first draft of the genome was announced in 2001 (Pilnick, 2002b), followed by a statement of completion in 2003. The prospect led Ridley to claim, "in just a few short years we will have moved from knowing almost nothing about our genes, to knowing everything" (1999:287). Consequently, Hicks, argued:

> genetic medicine is set to become one of the most important developments in health care, with advances in knowledge about the human genome affecting the treatment of common disorders such as diabetes, cancer and cardiovascular disease.
>
> Hicks, 2001:1564.

1.7. Hereditary breast and ovarian cancer.

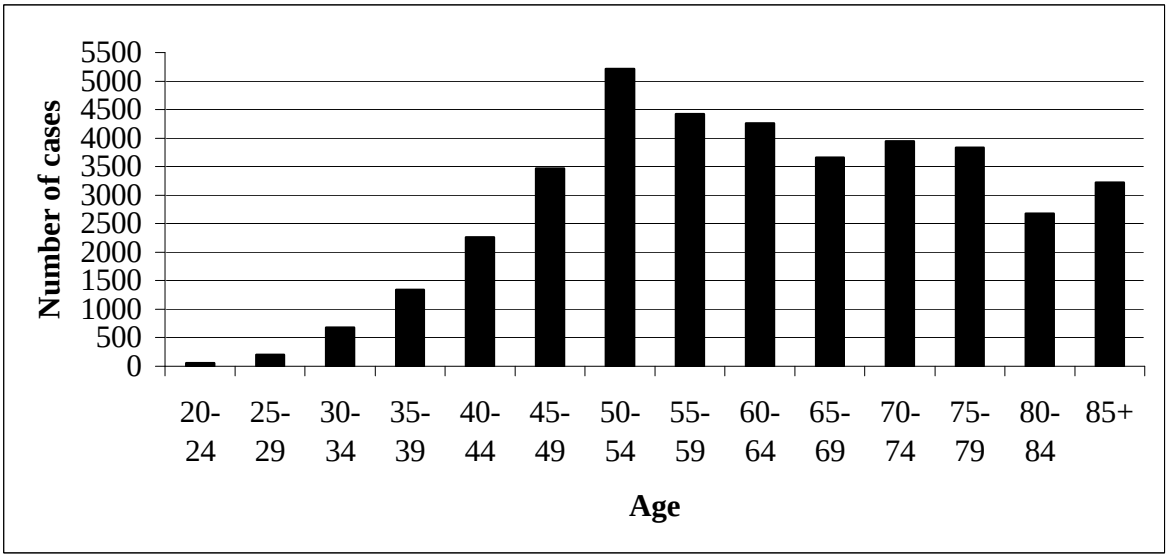
The growth in medical science, and particularly in genetics, has been exponential since the late 1980s. Due to advances made during the 1990s, it is now possible to predict whether an individual is genetically predisposed to developing certain diseases. Should a mutation be found, treatments can potentially be offered in advance of the onset of symptomatology. In the remainder of the chapter, I discuss the advances made specifically in relation to HBOC since the 1990s.

HBOC is characterised by its 'early onset'. Despite widespread agreement that hereditary cancer is characterised in this way, numerous definitions of early onset have been offered. For example, Meijers-Heijboer et al (2001) reported that women at-risk have an increased likelihood of developing breast cancer from the age of 25, whilst Evans et al (1994) suggested that early onset refers to disease that manifests before the age of 45. Accordingly, Gribble's suggestion that "women with BRCA1 or BRCA2 mutations are more likely to develop cancer at a younger age" seems to be the most encompassing description (1999:182).

The incidence of breast cancer has been linked to lifestyle and environmental factors (Mueller and Young, 1998), such as smoking (Band et al, 2002), alcohol (Department of Health, 2000) and consumption of dairy produce (Plant, 2000). However, other risk factors include age at onset of menstruation and menopause, number of pregnancies and use of oral contraceptives (Hopper, 2001).

Breast cancer is one of the biggest killers of British women (Dawson, 1990; Cancer Research UK, 2002b), affecting approximately 34,000 and killing 12,000 women per year (Patnick, 2000). Statistics suggest that between one in nine and one in 12 women will develop breast cancer within the course of their lives. The following chart illustrates the incidence of new cases of female breast cancer in 1998.

Figure three: Number of new cases of female breast cancer in the UK, 1998.



Source: Cancer Research UK, 2004a.

Given the increased incidence of breast cancer, as illustrated in figure three, the disease has become part of our everyday lived experience. Smith stated, "breast cancer touches nearly everyone in one way or another, either directly or through family and friends" (cited in Farrell Yelland, 2000:154). Most diagnoses are made in women over the age of 50, as figure three illustrated. Moreover, as figure four demonstrates, the risk of developing breast cancer increases with age.

Figure four: Estimates of the risk of developing breast cancer, by age.

Risk up to age 25 years old	1 in 15,000
Risk up to age 30 years old	1 in 1,900
Risk up to age 40 years old	1 in 200
Risk up to age 50 years old	1 in 50
Risk up to age 60 years old	1 in 23
Risk up to age 70 years old	1 in 15
Risk up to age 80 years old	1 in 11
Risk up to age 85 years old	1 in 10
Lifetime risk (all ages)	1 in 9

Source: Cancer Research UK, 2004a.

The population incidence of breast cancer, as illustrated in both of the previous charts, has been referred to as "sporadic" (Love, 1995:186), and accounts for "70% of breast cancer patients who have no known family history of the disease" (Love, 1995:186). Women at-risk of HBOC however, face substantially higher risks of both breast and ovarian cancer developing.

Ovarian cancer is currently the fourth most common female cancer in Britain, with approximately 7,000 cases diagnosed each year (Cancer Research UK, 2002a). Risk factors for ovarian cancer include age, family history and genetic predisposition, parity, menarche and undergoing prolonged fertility treatment (Cancer Research UK, 2002a). The average age of women developing ovarian cancer is between 50 and 65 years (Cancer Research UK, 2002; Stevens, 2002), although postmenopausal women are thought to be at greatest risk.

Figure five: UK incidence of cancer amongst women, 2000.

Breast	40,470	30%
Bowel	16,340	12%
Lung	15,160	11%
Ovary	6,730	5%
Uterus	5,620	4%
Non-Hodgkin's Lymphoma	4,380	3%
Melanoma	3,940	3%
Pancreas	3,650	3%
Stomach	3,570	3%
Bladder	3,210	2%
Other	33,080	24%

Source: Cancer Research UK, 2004b.

Currently, the only screening methods for ovarian cancer involve transvaginal ultrasound and the monitoring of serum CA 125 levels (Bennett et al, 1998; Swisher et al, 2001). However, neither procedure has assured efficacy in detecting the disease, especially in younger women, and are not thought to reduce mortality by any substantial amount (Lerner, 1998).

The problem of detection is exacerbated, as ovarian cancer does not cause any unique symptoms and the site is non-palpable, making identification and diagnosis problematic. These difficulties have meant that there is currently no national ovarian screening programme in the UK (Hallowell and Lawton, 2002; Stevens, 2002). Treatment for ovarian cancer routinely involves a full hysterectomy, in which the womb, ovaries and the fallopian tubes are removed, after which a course of radiotherapy and / or chemotherapy is undergone (Stevens, 2002).

1.8. Genetic causes of breast and ovarian cancer.

In 1990, King et al reported their influential observation that susceptibility to early onset breast cancer was linked to a mutation found in chromosome 17q12-21 (The Chemical Heritage Foundation, 2001). Later, Narod et al found that hereditary ovarian cancer could be explained by a mutation in the same gene (Bennett et al, 1999).

Miki et al (1994) were the first to isolate the gene, termed BRCA1. Later that year, a mutation on chromosome 13q12-13 was reported, and subsequently identified in 1995 as BRCA2 by Wooster et al (Bennett et al, 1999; Alderson et al, 2001). When functioning normally, BRCA1 and BRCA2 are tumour suppressor genes (Blanchard & Hartmann, 2000), preventing cancer from developing by regulating cell growth. Mutated genes can either be inherited or become damaged. Many reasons for such mutation to occur have been postulated, including diet, stress, trauma and environmental causes (Lerner, 2001b). However, the exact cause remains unknown. A mutation in a gene can result in an abnormal protein, which in turn can affect the growth and division of the cell. Hence, an abnormal - or mutated - gene is produced. Such genes account for up to 90% of HBOC (Katz Rothman, 1998).

Cancer statistics can be confusing, as the following illustrate. Hughes et al described how of all breast and ovarian cancers recorded, only:

> about 5%…are attributable to a mutation in…BRCA1. Women inheriting this gene mutation have an 80-85% life time risk of developing breast cancer and a 40-65% risk of ovarian cancer.
>
> Hughes et al, 1997:51.

Likewise, whilst Lerman and Croyle (1994) suggested that one in 300 women carry a mutated gene, a different slant sees that:

> given that 4-5% of breast cancer may be due to highly penetrant dominant genes, it is estimated that 13,500 women in the UK, aged 25-60 may be at increased risk of breast cancer.
>
> Hopwood, 1997:20.

Given the varying percentages suggested, there are unsurprisingly, conflicting interpretations regarding the level of a woman's risk of developing HBOC. Fentiman (1998) suggested that the lifetime risk of carrying a BRCA1 mutation is 56%, compared to the original risk of 85% given by Easton et al (1993). Therefore, current medical opinion declares that:

> the estimated risk of developing breast cancer associated with BRCA1 or BRCA2 mutation is 56% to 80% up to the age of 70 and the risk of developing ovarian cancer ranges from 16% to 40% by the age of 70.
>
> Metcalfe et al, 2000: 866.

However, BRCA1 and BRCA2 are only <u>two</u> of an unknown number of genes that can signify an increased risk of breast and ovarian cancer[7]. Together they account for up to 80% of all <u>inherited</u> breast and ovarian cancers, and up to 10% of the <u>total</u> number of breast and ovarian cancers. Because of developments in genetic medicine, it is now possible to sequence these genes to analyse whether or not a mutation is present (Esplen et al, 2000). Therefore, in time it is likely that other genes that signal a predisposition will be located and tested. Such genetic testing allows:

> individuals within identified 'cancer families' [to be offered] specific information about their risk of some forms of breast and ovarian…cancers.
>
> Bottorff et al, 1998:67.

[7] Other genes may be implicated in the development of breast and ovarian cancer; less frequently implicated genes include PTEN, p53 and ATM, whilst other genetic disorders, such as Li-Fraumeni Syndrome and Cowden's Disease also confer an increased risk of developing breast cancer (Astra Zeneca Pharmaceutics, 2002).

However, not everybody at-risk of developing HBOC is offered testing. Mutation searching is expensive and involves a difficult and lengthy process to isolate each gene. Moreover, as the statistics illustrate, BRCA mutations are rare; Parsons et al compared testing "to looking for a needle in a haystack" (2000:267). However, even if a positive mutation is found, the "clinical importance can be uncertain in the absence of a family history of breast and ovarian cancer" (Emery et al, 2001:57). As such, it is inappropriate to offer screening to the general population (Emery et al, 2001). Consequently, The Public Health Genetics Unit (2001) stated:

> genetic testing for hereditary mutations is only of use where there are strong indications from family history or clinical features that such a mutation is likely to be present.
>
> Public Health Genetics, 2001.

Therefore, to be offered genetic testing, the patient must be considered to be at high risk of developing HBOC. There are many definitions of 'high risk', but Blanchard and Hartmann (2000) provided a comprehensive chart (see figure six). They suggested that to be considered as at high risk of developing HBOC, the following factors should be present: early onset of disease, multiple cases of breast or ovarian cancer in the same individual or close blood relatives, clustering of breast cancer with other cancers that are linked to breast cancer, or a blood relative who carries a known genetic mutation.

Figure six: HBOC risk criteria.

1. Member of known BRCA1 / BRCA2 kindred
2. Personal history of breast cancer and one of more of the following: a. Diagnosed age 40 years, with or without family history. b. Diagnosed age 50 years or bilateral, with 1 close blood relative with breast cancer or 1 close blood relative with ovarian cancer. c. Diagnosed at any age, with 2 close blood relatives with ovarian cancer at any age, or breast cancer, especially if 1 woman is diagnosed before age 50 or has bilateral disease. d. Close male blood relative has breast cancer. e. If of Ashkenazi Jewish descent and diagnosed age 50 years, no additional family history required, or at any age if history of breast and/or ovarian cancer in close blood relative.
3. Personal history of ovarian cancer and one or more of the following: a. 1 close blood relative with ovarian cancer. b. 1 close blood relative with breast cancer at any age < 50 years or bilateral breast cancer. c. 2 close blood relatives with breast cancer. d. 1 close male blood relative with breast cancer. e. If of Ashkenazi Jewish descent, no additional family history required.
4. Personal history of male breast cancer and one or more of the following: a. 1 close male blood relative with breast cancer. b. 1 close female blood relative with breast or ovarian cancer. c. If of Ashkenazi Jewish descent, no additional family history required.
5. Family history only and one or more of the following: a. 1 close blood relative with breast cancer age 40 years or bilateral breast cancer b. 2 close blood relatives with ovarian cancer. c. 2 close blood relatives with breast cancer, especially if 1 is age 50 years. d. 1 close blood relative with breast cancer, 1 with ovarian cancer, any age. e. If of Ashkenazi Jewish descent, 1 close relative with breast or ovarian cancer.

Source: Blanchard and Hartmann, 2000:128.

Using a diagnostic blood test, the genetic composition of high-risk individuals is screened for mutated genes. Genetic testing involves:

> the analysis of a specific gene, its product or function, or other DNA or chromosome analysis, to detect or exclude an alteration likely to be associated with a genetic disorder.

Harper, 1997:8.

Test results are used to predict the risk a person has of developing a disease. Genetic testing for breast and ovarian cancer is a pre-symptomatic test, termed so as no

cancerous cells are expected to be present. This has led to what sociologists have suggested is "the geneticisation and concomitant medicalisation" of women (Hallowell, 2000:153), and the pathologising of the healthy breast (Lerner, 2001b). Subsequently, there has been a delineation between the categories of illness and wellness, leading Petersen and Bunton to describe:

> [the] redrawing of the boundaries between healthy and unhealthy people because, potentially, we are all unhealthy, or possible carriers of malfunctioning genes.
>
> Petersen and Bunton, 2002:37.

Whilst it has become technologically possible to screen for mutated BRCA genes, it is impossible to ascertain if the disease will develop, and if it does, whether it will manifest in the breast, ovary or both. Regardless, as the earlier discussion of the statistics illustrated, levels of penetrance are still high. Ponder and Green (1998) argued that 85% of women with mutated genes will develop either cancer. Therefore:

> mutation analysis of autosomal dominant hereditary breast/ovarian cancer genes [has become] an important technique for women at-risk.
>
> Lodder et al, 2001: 15.

Predictive, or pre-symptomatic tests have led to the "medicalisation of symptomless at-risk states" (Davidson et al, 1998:327). Whilst testing may look for something that "isn't there yet" (Katz Rothman, 1998:14), identification as a carrier of a BRCA gene can result in treatment that might be life saving or life maintaining. Hallowell explained:

> the rationale for screening high risk women is that cancer may be identified at an earlier stage when the prognosis is good, thus reducing the risk of dying from cancer.
>
> Hallowell, 1998:263.

Testing positive allows women to choose whether to undergo preventative surgery. Thus an outcome of genetic testing may be a reduction in the anxiety or uncertainty associated with the fear of developing cancer (Wood et al, 2000; Bebbington Hatcher et al, 2001; Clark et al, 2001). Alternatively, women may choose to undergo genetic testing with the aim of gaining reassurance that they are not at high risk of breast and

ovarian cancer, to avoid 'unnecessary' prophylactic surgery and to reassure other family members that they too are not at-risk (Ponder and Green, 1998). A more advanced discussion of women's rationales for undergoing testing and the decisions that they make following receipt of a positive mutation test result is made in chapters seven and eight.

1.9. Genetic counselling.

Prior to undergoing genetic testing, women are offered genetic counselling, in which "intense counselling regarding testing and risk assessment should be done, including psychosocial assessment and support, education and informed consent" (Blanchard and Hartmann, 2000:128). Armstrong et al (1998) suggested that genetic illness is not localised to the patient, but can also inform their relatives about their own risk of disease[8]. In turn, family members will have the option to 'empower' themselves (Lerner, 2001b) and choose whether they wish to undergo genetic testing and become aware of their own carrier status. BRCA testing may be declined in order to protect family secrets regarding maternity or paternity lines, or to enable insurance to be sought without difficulty. Other reasons cited for the decision to decline genetic testing include the maintenance of privacy, the right to confidentiality, the possibility of receiving false positive, or false negative tests, and the negative effects that testing might have on relationships (Clark et al, 2000).

Genetic counselling is the term used routinely to describe:

> multi disciplinary services, that encompass complete medical assessments, family history taking, genetic testing, disclosure of test results, psychological counselling and educational components related to prevention strategies.
>
> Bottorff et al, 1998:74.

A key component of genetic counselling is the information dissemination between the doctor and the patient. The stated aim of genetic counselling is for patients to be educated about their risk of carrying a genetic mutation and the consequences of this, providing patients with ways of coping with this risk and discussing ways that patients

[8] This is examined in depth in chapter five.

can adopt health-maintaining activities, such as lifestyle changes or undergoing prophylactic surgery. Genetic counselling also aims to provide patients with the tools required to reach a decision about their future, which they consider to be appropriate. Petersen and Bunton saw the role of genetic counselling as:

> the interface between scientists and 'consumers', in both the communication of risk information arising from genetic research and in offering support to those who are confronted with the attendant choices and dilemmas.
>
> Petersen and Bunton, 2002:135.

Nevertheless, a major challenge to genetic counselling is to ensure that all counsellees receive and understand the information that they require (Lerman and Croyle, 1994). As such, Bowles Biesecker and Marteau argued that further goals of genetic counselling include:

> facilitat[ing] informed and autonomous decision making, [an] appreciation of the inheritance of a genetic condition, [the] integration of genetic information into a useful framework, [and the] improvement in the emotional well-being of those affected or their family members.
>
> Bowles Biesecker and Marteau, 1999:133.

Consequently, Pilnick et al argued:

> genetic counselling is a process through which people affected by, or at risk of, a hereditary disorder are told about the possible consequences, the probability of developing or transmitting it, and the ways in which this may be prevented or ameliorated.
>
> Pilnick et al, 2000:3.

A central principle of genetic counselling is the provision of objective information (Michie and Marteau, 1998). Counsellors should give patients enough information to enable them to make a decision wisely, as opposed to a wise decision (Elwyn et al, 2001). Genetic counselling should be neutral and impartial (van Zuuren, 1997), and whilst talking to patients, counsellors should use clear and uncomplicated language. Genetic counselling should also aim to be client-centred and non-judgemental (Clark et al, 2001). Consequently, the practice aims to epitomise the ethos that patients ought to make their own decisions, as they alone know their feelings and beliefs better than

anyone else. Moreover, as I discuss in chapters seven and eight, it is the patient who has to live with the consequences of any decision that is made.

1.10. Risk-management techniques.

BRCA related cancers tend to be more aggressive than those developing sporadically (Garber, 1998), as they are:

> of a higher grade and contain more mitoses and nuclear pleomorphism than sporadic breast cancers.
>
> Blanchard and Hartmann, 2000:127.

Thus, given the fierceness of the cancers, being told that you are at-risk of developing HBOC poses a dilemma. Despite being "neither clearly ill nor clearly healthy" (Bains, cited in Fallowfield and Clark, 1991:71) current medical opinion favours three risk-management options following a positive BRCA test: extensive screening, via breast examinations and mammography, prophylactic mastectomy and oophorectomy, and chemoprevention, where pharmaceutical preparations such as tamoxifen are taken prophylactically. Each of these options are now addressed.

1.11. Breast screening.

Women at-risk of breast cancer can choose to undergo extensive surveillance; however, the efficacy of mammography in women under 50 years of age is questionable (Lucassen et al, 2001). 'Young' breast tissue is too dense for many abnormalities to be picked up before they develop into cancer. Moreover, some women fear exposure to radiation from X-rays because of their potential implication in the incidence of breast cancer (Blamey et al, 2000; Lucassen et al, 2001). Others still may find mammography uncomfortable, distressing, embarrassing or traumatic (Love, 1995; Glazer, 2000). Therefore, given that the uncertainty associated with breast screening is unacceptable for many people, prophylactic mastectomies are frequently considered to be the only reliable option available to women at high risk of developing breast cancer.

1.12. Surgical techniques.

Prophylactic mastectomy, defined by Blanchard and Hartmann as "the surgical removal of the breast when no breast cancer is present for the purpose of reducing the risk of developing breast cancer" (2000:129), can reduce the threat or incidence of breast cancer by between 80% and 90% (Hartmann et al, 1999; Metcalfe et al, 2000, 2002). However, total mastectomy, akin to that performed by Halstead, does not give women with breast cancer a significantly greater survival advantage compared to less extreme, more conservative measures, such as subcutaneous mastectomy (Kurtz and Kinkel, 2000; Lerner, 2001b). Blanchard and Hartmann explained:

> anatomically, breast tissue is known to be widely distributed over the entire anterolateral chest wall and axilla. Thus, no mastectomy can reliably remove all mammary tissue.
>
> Blanchard and Hartmann, 2000:129.

The most popular technique used whilst performing a prophylactic mastectomy is the total or simple mastectomy. However, it is also possible for a subcutaneous mastectomy to be performed prophylactically, although the procedure preserves as much as 10% of the breast tissue. Consequently the procedure carries a greater risk of breast cancer developing compared to prophylactic total mastectomies.

The term mastectomy describes a wide variety of surgical techniques that involve different amounts of breast tissue being removed, in addition to the excision of the lymph nodes, the nipple and the areola. Although the terms are used interchangeably, the 'total', 'simple', 'Halstead' or 'radical' mastectomy removes between 95% to 99% of breast tissue, including the nipple, areola, and depending upon the individual case, the pectoral muscle. In comparison, the 'subcutaneous' mastectomy removes between 90% to 95% of breast tissue, using an inframammary incision. This procedure differs from the 'radical' mastectomy, as the surrounding skin, the nipple, the areola and the pectoral muscle remain intact (Metcalfe et al, 2002).

Eeles (2000), Hartmann et al (2000) and Lloyd et al (2000) all reported that breast cancers have developed following bilateral mastectomies, leading some commentators

to question the rationale for undergoing risk-reducing surgery (Gardner, 1997). Thus Stefanek et al (2001) called for the procedure to be re-termed a 'risk-reducing mastectomy' rather than a 'prophylactic' mastectomy. Fumento (2002) consequently remarked that all that can be certain about such procedures is that they involve "lopping off" one's breasts. Given the possibility that breast cancer may still develop following a prophylactic bilateral mastectomy, one should question why it is popular amongst women at-risk of HBOC. Moreover although prophylactic mastectomy has advantages, its long-term efficacy is unknown (Lerman and Croyle, 1994).

If women choose surgical intervention for its protective function against the risk of developing ovarian cancer, current medical practice suggests that a prophylactic oophorectomy is the most appropriate technique. The procedure is only performed if the woman has finished her childbearing, as it removes the reproductive organs resulting in infertility and induces, albeit surgically, a premature menopause. Prophylactic oophorectomy is believed to be more effective in preventing cancer compared to the available surveillance measures and is widely advocated, as "about 75% of all ovarian cancers have spread by the time they are discovered [and] the five-year survival is about 44%" (Kelly, 1999:54). However, the following chart depicts an even lower five-year survival rate.

Figure seven: Five-year cancer survival rate for women in England and Wales, 1991-1993.

Malignant Melanoma	85.6%
Breast	73.7%
Body of Uterus	73.1%
Bladder	57.6%
Non-Hodgkin's Lymphoma	47.7%
Rectum	42.5%
Colon	42.2%
Ovary	29.2%
Stomach	10.5%
Lung	5.0%
Pancreas	2.1%

Source: Cancer Research UK, 2002.

In light of the claims that current screening options offer no effective safeguard against the risk of developing ovarian cancer (Berchuck et al, 1999), Grann et al (2002) suggested that women opting for preventative treatment are more likely to survive longer compared to those women choosing surveillance. However, Swisher et al highlighted that "prophylactic oophorectomy is not 100% protective as women remain at some risk of developing primary peritoneal cancer" (2001:88).

1.13. Oncology chemotherapy.

'Chemoprevention', first used in the 1970s (Jordan and Morrow, 2002), describes "a drug induced block or reversal of precancerous progression leading to decreased incidence or delay in the appearance of invasive cancer" (Fabian and Kimler, 2001:312). Hershman et al (2002) reported substantial decreases in the risk of developing breast cancer when the chemotherapy medication tamoxifen was taken prophylactically. They suggested that women aged between 35 and 44 years old when they started taking chemoprevention were 44% less likely to develop breast cancer. The figure rose to 55% for women aged 60 years and over. In the UK however, no drug has been specifically licensed by the Medicines Control Agency, now the Medicines and Health Regulatory Agency, for chemopreventative purposes. Therefore, should women choose this treatment, their only option at present is to enrol in a clinical trial.

In this chapter, I have shown that the treatment of breast and ovarian cancer has varied over time. However, in contemporary society, there appears to be little consensus on how to treat breast and ovarian cancer, whether symptomatically or pre-symptomatically. Fallowfield et al (1994) reported that the options women received once diagnosed with breast cancer are dependent upon the method favoured by individual surgeons. Rather than there being one 'correct' treatment path for each disease, doctors are free to choose different therapy regimes. Thus, whilst medical knowledge is used to assess which treatment offers the best efficacy in each unique case, there appear to be contesting opinions regarding which is the most appropriate and efficacious therapy to offer to women with or at-risk of breast cancer. Nevertheless, most women at-risk of HBOC are subjecting themselves to expert medical knowledge that suggests that extensive surgery is the most effective way to stop the manifestation of a cancer. However, it should be remembered that this is a cancer that is not yet present, nor possibly will ever be.

In the next chapter, I review the literature discussing women's reactions to being at-risk of HBOC, the effect that carrier status has on their everyday lives and the decisions that they reach regarding whether or not to undergo risk-management treatment.

Chapter Two. The Psychosocial Impact of Hereditary Breast and Ovarian Cancer.

> Until now, breast cancer as a subject has been orphaned, separated from the mainstream literature of history and sociology, just as the experience of the disease itself has been cordoned off from society, a private experience suffered by women individually, at the margins of public consciousness.
>
> Leopold, 1999:3.

In the previous chapter, I reviewed the key points in the medical history of breast cancer. In this chapter, I concentrate upon the effect that being at-risk of HBOC can have upon a woman. I discuss how women's reactions to, and experiences of being at-risk of HBOC have been reported, and outline some of the implications of the decision to undergo risk-reducing surgery. Accordingly, I examine the effect of prophylactic and reconstructive breast surgery, and the medicalisation of women's bodies. During this examination, I draw upon themes including women's perceptions of their femininity, sexuality and body-image, which are addressed in relation to the risk or diagnosis of breast and ovarian cancer. The chapter is structured in the following manner:

2.1. Contemporary depictions of breast cancer.
2.2. Women's worries, anxieties and perceptions of risk.
2.3. Decision-making and risk-reducing strategies.
2.4. Risk-reducing strategies and femininity, sexuality and body-image.
2.5. Effects of the medicalisation of women's bodies.

2.1. Contemporary depictions of breast and ovarian cancer.

Traditionally, breast cancer has been feared, viewed with suspicion and considered to be a taboo subject (Farrell Yelland, 2000; Saywell et al, 2000). People spoke of 'the big C', 'women's disease' and even 'it' (Kramer Brown, 2000). Consequently, before the high profile breast cancer cases of women considered to have a prominent position in (American) society, including Happy Rockefeller, Shirley Temple Black and Betty Ford, breast cancer was rarely openly spoken about (Weisman, 2002). In the UK however, fewer women appear to be prepared to publicly acknowledge their cancer.

Despite this, breast cancer has started to become less of a taboo subject in contemporary western society.

Some women openly discuss their experiences of the disease and its treatments, in magazines, television programmes and amongst one another. Large-scale media campaigns, such as breast cancer awareness month held annually each October, the provision of pink ribbons and the 'fashion targets breast cancer' campaign have all helped to raise public awareness of the disease and enable it to be depicted as a 'normal' disease which need not be hidden. Comparably, ovarian cancer is almost overlooked. Whilst 'ovarian cancer awareness month' does exist, and is publicised by turquoise ribbons, its visibility and public awareness of it, is low. In this chapter therefore, it is not that I have overlooked, or forgotten to discuss the psychosocial impact of ovarian cancer, or have overly focused upon breast cancer. Rather, the majority of the literature on the psychosocial effect of being at-risk of HBOC concentrates upon the risk of breast cancer. Where ovarian cancer is mentioned, I have of course included it within this review.

Throughout this thesis, I demonstrate that our understanding of, and reactions to breast and ovarian cancer, is socially constructed. For example, the manner in which breast cancer and women's breasts are depicted in the 21st century has altered greatly compared with that seen previously; today, women may choose to speak openly about their breast cancer, and women's breasts are neither hidden nor obscured. In contrast, only a few decades ago, breast cancer was associated with shame and the breasts were concealed (Reibstein, 2002). Consequently, our understanding is influenced by contemporary cultural assumptions, biases, knowledge, perceptions and experiences of both the breast and breast cancer, the ovaries and ovarian cancer. Thus, in reviewing the psychosocial impact that breast and ovarian cancer is reported to have upon women, it is vital to remember that the arguments made are contextually linked to a certain point in time.

2.2. Women's worries, anxieties and perceptions of risk.

In this section of the chapter, I review the existing literature in regards to women's experiences of being told that they are at-risk of developing HBOC, with specific focus

on their worries, anxieties and perceptions of both being at-risk and of risk itself. This body of literature, and outcomes such as those mentioned above, are typically referred to by utilising the term: 'psychosocial', although an agreed and concrete definition of the term is missing from the literature. In utilising the term 'psychosocial' within this thesis, I do not wish my discussion to be read as an endorsement of the field, but rather as an attempt to show familiarity and consistency with the existing knowledge. Moreover, as I demonstrate later in this chapter, I perceive the existing body of work critically, and reflect on the methodological weaknesses inherent within it.

Risk is a "defining cultural characteristic of western society at the end of the 20th century", and has "become a common construct around which health in western society is described, organised and practised, both personally and professionally" (Robertson, 2001:299). Risk can act as a reassuring influence, but also an unsettling one; both notions of risk however, are associated with anxiety (Wilkinson, 2001; Hallowell et al, 2004). Hallowell et al described how when risk was described in these terms, it was used in relation to predict future events, and so might be considered "beneficial" (2004:554) or to raise awareness of an unwanted outcome, and thus be "potentially threatening" (2004:553). When people are told that they are at-risk of developing a disease, they inhabit a "state of being" where you are neither ill nor healthy (Robertson, 2001:296); they are at-risk, they are waiting for cancer to possibly develop. Consequently, being told that you are at-risk of HBOC has been likened to the threat of "Damocles' sword, hanging over the lives of women with family histories" (Pistoi, 2001).

Women's responses to the news that they have a heightened risk of developing HBOC vary. For some, the 'diagnosis' might be an "emotional catastrophe; for others, it represents yet one more problem to face alongside many other social difficulties in their lives" (Fallowfield, 1999:1). Despite these varying reactions, much of the existing literature has concentrated solely upon women's responses in relation to the level of anxiety or psychological distress experienced (for example, Watson, 1999; Meiser et al, 2000; Lodder et al, 2001).

Wilkinson and Kitzinger argued, "breast cancer is not just physically traumatic, but also causes tremendous emotional distress" (1996b:124). Trask et al consequently termed

such anguish as “cancer-specific distress” (2001:350). Many authors have described the high levels of worry and anxiety that women at-risk of HBOC have been found to exhibit. Wardle described anxiety that reached “pathologic proportions” and referred to this as “cancerphobia” (1995:81). In turn, Robertson suggested that ‘breast worry’ embodies “three essential components” (2001:297), consisting of “the inevitability of breast cancer, the constancy of this worry about breast cancer and the sense of the breasts as flawed body parts” (2001:297). These three themes are addressed throughout this chapter, and discussed in relation to women’s accounts of their surgical decision-making, in chapter eight.

i. Methodological weaknesses.

Much of the existing literature detailing women’s reactions to being at-risk of HBOC has set out to investigate women’s social and psychological responses to the news that they carry a mutated BRCA gene. However, the methodologies employed in such studies have removed the woman and consequently have neglected the personal experience from the arguments made; much of the existing literature examining women’s reactions to their genetic risk has relied upon measurement[9]. In the following section of this chapter, I critique the methods previously utilised.

Of the measurement strategies utilised, the Roter Interaction Analysis System (RIAS) is the most widely used classification (Roter and Larson, 2002). Those employing the RIAS categorise data into “socio-emotional and talk-focused elements of medical exchange” (Roter and Larson, 2002:243), including: personal remarks and social conversation, laughs and jokes, agreement or understanding, empathy, partnership, self-disclosure, orientation or instruction, asking for understanding, asking for opinion, open-ended questions, and closed questions (Sandvik et al, 2000). For example, Ford et al analysed tape recordings of consultations using the RIAS, and “every utterance was coded into one of 34 mutually exclusive content categories” (1995:2265). Verbatim transcriptions were cut, and fitted into a small number of analytical categories. Therefore, quantitative ‘code and count’ methodologies have been utilised to analyse

[9] Butow et al (2003) have comprehensively reviewed the use of quantitative scales whilst investigating women’s reactions to genetic risk.

predominantly qualitative data. Such quantitative methods focus on outcome measures of being at-risk, rather than the at-risk experience as a process. Therefore, like Clarke et al, who described how, "current practice is to focus on quantitative methods, assuming that benefits exist only if they can be counted" (1996:468), I am critical of the existing body of knowledge in respect to its failure to look beyond the quantifiable. To this extent, I support Cox and McKellin's statement that, "lay risk is not objective, cannot be quantified or measured, and is not static, it must be understood as a dynamic experience of personal uncertainty about one's own, and….one's family members' future" (1999:624).

Despite the attempts of Clarke et al (1996) and Cox and McKellin (1999) to draw attention to the methodological weaknesses of the existing body of literature, researchers continue to follow the trend whereby women's reactions to HBOC are subjected to pre-coded analytic categories. To confound this weakness and move further away from women's own accounts of their at-risk experience, many of the questions posed by research teams have been designed around quantifiable trait scales that impose values onto women's responses and read meaning from the numbers returned, rather than draw meaning from the women's own narratives (or accounts) of the event.

To demonstrate how the use of trait scales are lacking whilst addressing women's experiences of being at-risk, Lodder et al's (2001) examination of women's anxiety and depression following awareness of their genetic risk provides a useful example. Lodder et al utilised the Hospital Anxiety and Depression Scale (HAD) to examine women's levels of distress following genetic testing. The HAD questionnaire utilised two scales of seven items; each question had four possible answers which could be scored between zero and 21; scores over 11 were considered to demonstrate that the person was clinically anxious or depressed, whilst scores between eight and ten were judged as indicating that the patient had 'borderline' anxiety or depression.

Lodder et al's conclusion that women's feelings of anxiety and depression rose following receipt of a positive BRCA test, while levels decreased in non-carriers is not unexpected. However, such methods provide no detailed insight about the characteristics of the anxiety or depression experienced by the women. To gain a detailed insight into women's experiences, one must employ research methods that

allow individual experiences to be recognised.

Given that women's own narratives or accounts are rarely heard or discussed in the existing body of literature on reactions to being at-risk of HBOC, it is imperative to question who decides what psycho-social categories should be discussed, and linked to this, which utterances fit into these categories. In critiquing the existing body of literature, the problem therefore stands with the act of coding and the assumption that prior coding can determine the meanings of the utterances received during data collection, as well as the suggestion that understanding can be gained from objective, quantifiable and measured outcomes. Psathas (1995) offered a critique of such research, attacking the reductionist nature of the coding systems, the ability to ignore the influence of the local context, and the quantitative bias towards data that can be counted and presented in the form of frequencies.

In addressing women's experiences of being at-risk of HBOC, this thesis is written from a standpoint that acknowledges the need to understand the complex social influences that any social event or interaction is likely to be shaped by. Consequently, it is held that all those methods that have been favoured previously are only able to provide a snapshot of a particular event, which is held at a particular point and interpreted according to an outsider (the researcher/research team). Accordingly, we must approach the existing body of literature with caution; the quantifiable data collected by such methods may have nothing to do with how the woman might actually feel or perceive her situation. In examining women's experiences it is therefore felt to be important that the methods utilised allow talk to be seen. Yet as I discuss later in the thesis, talk is never neutral or objective, but is a form of self-presentation, or self-protection (Goffman, 1959).

Having addressed the methodological weaknesses of the existing body of literature, I now turn to this corpus of work, and summarise some of the main empirical conclusions that have been offered. Many of these themes will be returned to in the course of the thesis, but upon their readdress, will be considered in light of data that has been collected utilising a methodological approach that values women's own words, via the accounts that they offered during the interviews and observations of consultations.

ii. The existing 'psychosocial' literature.

According to the existing corpus of literature on women's reactions to being at-risk of HBOC, women with a family history of cancer are found to have a greater chance of experiencing psychological distress, anxiety and feelings of vulnerability related to concerns about their family's history of the disease (Kash et al, 1995; Meiser et al, 2000; Conto and Myers, 2002; Foster et al, 2002). Such distress, anxiety and vulnerability can create emotional problems, including sadness, anger, depression, guilt and fear (Clark et al, 2000). Rabinowitz summarised the various psychosocial effects that a breast or ovarian cancer diagnosis may create, and stated:

> it is well accepted that women may experience a sense of alienation, decreased self-esteem, hopelessness, anxiety, depression, hostility and guilt following diagnosis of breast cancer.
>
> Rabinowitz, 2002: 140.

In an attempt to lessen some of these reported psychosocial effects, once women have learnt that they are at-risk of developing HBOC they are offered breast and ovarian screening. However, screening does not always provide peace of mind longed for or reduce the levels of cancer-related anxiety experienced. Duncan et al argued, "screening may…exacerbate anxiety and uncertainty" (2001:180). Bish et al (2002) suggested that anxiety relating to being at-risk of HBOC may lead some women to be non-compliant with the routine screening offered to them, whilst others may become overly pre-occupied with carrying out breast self-examinations (BSE).

Supporting Bish et al's (2002) assertion regarding how some women may become fixated about carrying out BSE, Kash et al commented that some women at-risk of HBOC "do not wonder <u>if</u> they will get breast cancer but rather <u>when</u> it will appear" (1995:74; original emphasis). Women at-risk have been found to frequently over-estimate their chance of developing HBOC (Metcalfe and Narod, 2002; Andersen, 2002; Spurgeon, 2002), and this is often related to a high level of anxiety about cancer developing (Meiser et al, 2000). Therefore, the development of cancer appears to be not so much of a real possibility, albeit one with a high probability, but an inevitability: it <u>will</u> develop.

Metcalfe and Narod (2002) investigated the subjective risk estimates of women who had undergone bilateral prophylactic mastectomies. They reported that women estimated their personal risk of developing breast cancer to be 75.4%. However, when the same authors re-calculated the women's risk with their own epidemiological statistical based models (the Gail model, the Claus model and the BRCAPRO model), the average estimate of risk was just 17.2%. The discrepancies between these figures were defended in relation to the second figure being based upon an average given by statistical models of epidemiological measures of risk. Although the epidemiological models could offer statistical probabilities, they could not explain an individual's subjective perceptions and understanding of being 'at-risk'. It is postulated therefore, that this difference demonstrates a further example of how quantitative scales and measurements cannot adequately account for women's experience of being at-risk of HBOC.

Andersen et al (2002) investigated women's worries about ovarian cancer risk, using a series of quantitative measures. Women were asked to rate their likelihood of developing ovarian cancer from zero, meaning no chance of cancer developing, to 100, signalling that they thought that they would definitely get cancer, and the frequency that they worried about developing ovarian cancer, from "rarely or not at all…. to almost all of the time" (Andersen et al, 2002:5). Andersen et al concluded that women had "unrealistic beliefs about their risk of ovarian cancer" (2002:6). The wide discrepancies between the statistical probability of cancers developing and women's perceptions of their risk illustrates the differences between scientific or medical understanding of breast and ovarian cancer risk, and that of women who are at-risk themselves. Risk is neither objective nor static, but is socially constructed and is shaped by the contexts in which it occurs. Whilst statistical based estimates of risk can be given, women will understand and come to terms with their perceived level of risk in their own way. The predominance of trait scales and quantifiable measures in the existing body of literature has enabled the important difference between objective and subjective risk to be overlooked.

One outcome of women's risk perception frequently reported in the literature is that their 'risky' bodies were flawed and dangerous. Bodies were described as being 'out of control' and as 'biological timebombs' (Hallowell, 2000b). Consequently, the provision

of prophylactic surgery provides women with "the opportunity to prevent cancer occurring and thus [enables them] to take control of what they perceive as their destiny" (Hallowell, 2000b:162). Hallowell and Lawton (2002) furthered this argument, deeming that prophylactic surgery was a form of empowerment for women at-risk. Surgery allowed women to regain control and manage their future risk, resulting in a "secure and viable social self" (Hallowell and Lawton, 2002:438). As such, whilst prophylactic surgery was acknowledged as a "radical or drastic action" it was justified "on the basis that elimination of the 'dangerous' organs would remove their fear of developing cancer" (Langellier and Sullivan, cited in Hallowell, 2000b:161-162). However, given the uncertain efficacy of prophylactic surgery, Hallowell and Lawton's description that the result of surgery will be a "secure and viable social self", is questionable. Even if undergoing a prophylactic mastectomy and oophorectomy, a woman's future may not be "secure" as cancer can still develop. Moreover, as I discuss later in the chapter, post-surgery, women might have doubts about the "viability" of their bodies. Therefore, although some women might consider prophylactic surgery to be empowering, it is important to recognise that it is not without its dangers and risks.

2.3. Decision-making and risk-reducing strategies.

Women found to be carriers of a positive BRCA mutation are offered prophylactic surgery. However, as I discussed in chapter one, prophylactic surgery cannot totally eliminate a woman's cancer risk; although she might have a mastectomy, up to 10% of the breast tissue will remain on the patient's axilla, and despite having an oophorectomy, ovarian cells can remain in the peritoneum and develop into cancer. Fry et al explained that following oophorectomy, there was an "unquantified risk" of peritoneal cancer, which "clinically and histologically resembles ovarian cancer" (2001:232). Nevertheless, for many women at-risk of HBOC, the decision to undergo prophylactic surgery is argued to be the best way of "reducing [their] anxiety about cancer as well as reducing the risk itself" (Hopwood et al, 2000:463).

In chapter one I described how, should a woman receive a positive BRCA mutation test result, current medical opinion favours prophylactic mastectomy and prophylactic oophorectomy, if she has finished her childbearing. However, as "clinical criteria alone do not favour one treatment…patient participation in choice of treatment is frequently

advocated" (Kenny et al, 1999:160). Yet, risk-reducing surgery in relation to HBOC is in its early stages, and:

> women found to be at-risk for breast cancer will be forced to make difficult decisions about the use of controversial preventative measures such as prophylactic mastectomy or experimental chemopreventative drugs.
>
> Asch and Geller, 1996:333.

Current prophylactic, or risk-reducing techniques might be considered 'controversial' or 'experimental' for many reasons. Whilst investigating the psychosocial outcome of women undergoing prophylactic oophorectomy compared to ovarian screening, Fry et al argued that when faced with news they are carriers of a positive BRCA mutation, women confronted "stark choices" (2001:231). Women can 'do nothing' (Charles et al, 1998), have their ovaries removed and hence compromise their fertility and ability to bear children, or have their breasts amputated. In contrast, others see no need to undergo surgery to combat a disease that is not present, claiming "if it's not broke don't fix it" (Hallowell, 1998:268). As I demonstrate later in the chapter, much of the literature on prophylactic surgery has concentrated upon how mastectomy and oophorectomy might lessen a woman's perception of her femininity and womanhood. However, "breast cancer is not really about breasts, it's about life and death" (Potts, 2000:55). Moreover, given the low five-year survival rate of ovarian cancer (see chapter one, page 38), Potts' argument regarding treatment decisions being about life or death, is possibly more significant for women at-risk of ovarian cancer.

Whilst the social, psychological and emotional impacts of oophorectomy and mastectomy are likely to be devastating, it is probable that they will be considered preferential to the possible alternative outcome: cancer, metastasised cancer and loss of life. Describing her rationale for having a mastectomy, Sue stated, "the bottom line to me is life…. with taking the breast, I had a better chance of survival" (Sue, cited in Kasper, 1995:209). Similarly, Lloyd et al explained that "prophylactic mastectomy may be construed as a 'last resort' to ensure survival and counter 'the final loss', their own life" (2000:482). Therefore, prophylactic surgery is seen as the best way to lessen the risk of cancer developing and reduce levels of cancer-related anxiety (Bebbington Hatcher et al, 2001); many women appear to believe that it offers them the best chance of survival.

Prior to a woman consenting to undergoing prophylactic surgery, Blanchard and Hartmann considered that:

> efforts need to be made to educate and inform her of the risks, benefits and potential complications. In clinical decision-making, the significant reduction in risk associated with the procedure must be weighed with other factors, including the desire for reconstruction, the effect of the surgery on a woman's body-image and sexuality, the irreversibility of the decision, and the realisation that breast cancer would not have developed in a proportion of the women who undergo the procedure.
>
> Blanchard and Hartmann, 2000:133.

Despite the efforts to educate and inform women about the risks involved in surgery that Blanchard and Hartmann outlined, Lloyd et al (2000) observed that some women with a positive BRCA mutation felt forced to undergo prophylactic surgery. Moreover, Charles et al (1998) argued that for some women 'doing nothing' to combat their risk, was considered to be an unacceptable option. As I discuss in chapters seven and eight, factors influencing women's HBOC decision-making include their obligations towards their family, wanting to take control of the cancer, the efficacy of screening, their fears and anxieties relating to HBOC, and the threat that cancer and its therapies would pose to their perceptions of their sexuality, femininity and fertility. Foster et al (2002) reported that women at-risk were acting altruistically by considering others when they made their decisions to undergo prophylactic surgery. Hallowell et al (2001) furthered this argument, and commented:

> high risk women frequently describe themselves as having an obligation to their family to manage their cancer risks…..none of the women in the surgery group described their decision to undergo surgery as a decision they made just for themselves; indeed nearly all the women said that they had a responsibility.
>
> Hallowell et al, 2001:687.

Such responsibilities determine women's actions to regain control over their 'out of control' bodies. However, whilst some women might make the decision for altruistic reasons, the implications of the decision will affect themselves first of all.

2.4. Risk-reducing strategies and femininity, sexuality and body-image.

Donna Dawson:	You think if you've got no uterus and no breasts you're still technically a woman?
Erin Brockovich:	Sure you are. You're just a happier woman, 'cos you don't have to worry about maxipads and underwire.

Source: 'Erin Brockovich', Columbia Pictures, 2000.

In this section of the chapter, I address the impact that mastectomy and oophorectomy is reported to have upon women's perceptions of their femininity, sexuality and body-image. In the existing literature, these three terms face a similar problem to that experienced by the term 'psychosocial': they are frequently offered, yet rarely defined. White drew attention to this, commenting how "the literature in psychosocial oncology has not always clearly defined what is meant by body-image…the term is used interchangeably to refer to different aspects of psychological adjustment to cancer, such as sexuality, self-esteem or stigma" (2000:183). Body-image is not solely associated with an individual's appearance, to themselves or others, but can also be related to their satisfaction, approval and a general sense of well being (Bredin, 1999). The term femininity is used in a variety of ways to refer to femaleness, womanhood, womanly 'qualities' and characteristics, and can also be linked to discussions of body-image. Lastly, the term sexuality is used to discuss women's perceptions of their body as a sexual entity and their relationships with spouses. Harwood and O'Connor (1994) argued that sexuality should be recognised as something more than a biological or physiological entity. Rather, they suggested that the term sexuality should be understood in relation to the "entire context of women's lives, relationships and emotions".

i. Mastectomy.

> The emphasis on sexuality and body-image – meaning being attractive to men and engaging in sexual intercourse with them – is major preoccupation of the psychiatric and psychological literature on mastectomy. There is very little discussion of other issues in relation to breast loss – breast feeding, or explaining (of concealing) the loss of a breast to a child, for example.
>
> Wilkinson and Kitzinger, 1994:126.

I have argued that much of the literature on the psychosocial impact of prophylactic surgery appears to be swayed by the perception that "beauty and the female body go hand in hand" (Davis, 1995:39). Within such an observation, the presence and appearance of the breast has been most fundamental. Davis described the breasts as "irrevocably linked with cultural notions about femininity" (1995:9), whilst Saywell et al (2000) described breasts as "iconic of female sexuality" (2000:39). These statements help to reinforce my earlier argument that our understanding of breast cancer and breasts is shaped and constructed by contemporary, western society. Kasper reinforces this position, having argued:

> Society's calculus of women's worth: a woman is only as good as she looks. To lose a breast, then, poses not only the threat of a cancer death but also the loss of the self as well.
>
> Kasper, 1995:210.

Potts (2000) suggested that the ideal woman, and the idealised image of femininity, is represented by the notion of a two-breasted, symmetrical 'beauty'. Kasper and Ferguson (2002) extended this description, commenting that 'womanly' qualities might include physical attractiveness, being sexually inviting and appearing to have maternal instincts and feelings. Hence, descriptions of femininity often centre upon the body as the key-defining characteristic of women and womanhood (Saywell et al, 2000). Within this focus on the body, much attention has been placed on the breasts. Bertero considered:

> [the] breasts seem to have a unique feminine value, which gives the women value as women and gives them their self-value…..breasts seem to symbolise the woman as a nurturer and also her maternity, but they are, in addition, a symbol of erotic pleasure.
>
> Bertero, 2002:360.

Bertero's criticism that women's worth and value is placed upon the breasts is echoed by Kasper (1995), who condemned:

> a culture that places high value on breasts as a part of the female form and persona. It is not simply that breasts are admired, valued, viewed as objects of beauty, or conversely, are not. By extension, women themselves are admired, valued, viewed as objects of beauty, or not, in large measure because they have breasts.
>
> Kasper, 1995:198.

Yet 'being' a woman is more than just having breasts. In her qualitative interview study with breast cancer patients, Kasper recalled the account given by Dee. Dee had been diagnosed with breast cancer, and following her mastectomy had chosen not to have breast reconstruction. She defended her decision by arguing that her breasts were not what made her a woman. She stated, "I don't have to think 50 times a day, I am a woman" (Dee, cited in Kasper, 1995:213).

Breasts have no intrinsic physical value or worth beyond providing a means to nourish newborn babies. Yet breasts have become objectified and fetishised, and have been constructed as the key defining feature of a 'woman'. Breasts are seen to have nurturing and sexual qualities (Leopold, 1999), and have an emotional and symbolic significance (Bredin, 1999). Broom considered that society's reaction to breast cancer is related to "the particular geography of breast cancer [which] presents special complications because of its location at the site that is culturally coded feminine but ambiguously both maternal and erotic" (2001:258). Accordingly, Kasper argued, "today's culture creates a social context in which breast loss appears to have dire consequences for women" (1995:197).

A recurring theme in the literature is the description of breasts and ovaries as 'womanly bits' (Hallowell, 1998; 2000a; 2000b). Rosenbaum and Roos suggested that women have little option but to accept this stance concerning their breasts, as:

> the values placed on breasts and their assumed link to femininity, sexuality, identity and self-worth are consistently presented to women.
>
> Rosenbaum and Roos, 2002:154-5.

With such a perceived value and worth placed on the breasts it is unsurprising that society sees "the surgical alteration or removal of the breast as part of treatment for breast cancer….as significantly decreasing a woman's femininity, sexuality and overall self-esteem (Rosenbaum & Roos, 2002:155). As a result, one might sense that our "society's vision of femininity is not tied up with what's inside, it's what's on the outside" (Hallowell, 1998:270). Accordingly, it has been suggested that post surgery, the mastectomised woman may feel less feminine (Pernet et al cited in Hallowell, 1998). Hallowell considered:

> one's femininity is, at least in part, dependent upon having a particular type of body - body with breasts. Breasts are frequently described as 'womanly bits', and removing them was perceived as a threat to one's feminine body-image - one's femininity.
>
> Hallowell, 2000:165.

Rosenbaum and Roos argued, "women must grapple with the meaning of their breasts as defined through their experiences and society" (2000:154). Hallowell's description tells us that a breasted and fertile body is vital to be recognised as a woman. Therefore, for some women "the worst part of having a mastectomy is that you just don't feel feminine" (Berger and Bostwick, 1998:384). Mastectomies compromise women's identity through removal of the breasts and chemotherapy can lead to hair-loss. In contemporary western society, having two breasts is an important part of female identity and "the mastectomised woman may look different" (Hallowell, 1998:273). Saywell et al depicted mastectomies as a violation of femininity, portraying the procedure as:

> an assault on beauty and perceptions of normality….like other forms of amputation, perceptions of mastectomy and lumpectomy are governed by ideas about disfigurement, damage and mutilation. Its associations are with disease and not recovery.
>
> Saywell et al, 2000:42.

Bertero extended this argument, describing how cultural perceptions of "beautiful, perfect female bodies with nice breasts", do not mesh with the post-mastectomised body, where the "body [is] ugly, with a big scar where there was supposed to be a breast" (2002:360). Consequently, Reaby argued how:

> cancer of the breast is unique. Not only does this disease cause pain, suffering and the possibility of death, but it also imposes a potential threat to a woman's perception of herself through an attack on a part of her body that is endowed with the symbolic significance of femininity and womanliness.
>
> Reaby, 1998:252.

Reaby's quotation emphasises the threat which breast cancer can evoke for some women; the disease, and the threat of the disease both have the ability to attack the symbols of femininity and womanliness: the breasts. Yet, for other women, the reaction to mastectomy contrasts starkly. Many such accounts of the post-mastectomy experience can be found in the existing literature, with typical comments including: "it's not as bad as I thought. Just one side of me looks like a boy with stitches across" (Sally, cited in Kasper, 1995:207), and "I don't define myself [by my] boobs really, I see myself as a person" (unnamed respondent, cited in Lloyd et al, 2000:478).

Despite these accounts, which imply that mastectomy had little impact on some women's social selves, the social, emotional and psychological side effects of mastectomy should not be underestimated. Al-Ghazal et al (2001) suggested that negative psychological and sexual outcomes following mastectomy are usual. Similarly, whilst investigating mental health and body-image outcomes in women following bilateral prophylactic mastectomy, Hopwood et al reported that women recounted instances of:

> decreased sexual attractiveness, reduced physical attractiveness, self consciousness about appearance, decreased satisfaction with body and feeling less feminine.
>
> Hopwood et al, 2000:467.

Hence, it appears that "breasts do not just make bodies look feminine, [but] having breasts also makes one feel like a woman" (Hallowell, 2000:172).

An integral factor in women's ability to look and feel like a 'woman' following mastectomy, was the effect that the lost of breasts would have upon her sexuality, as mastectomy amputates an erogenous zone of the body (Kasper, 1995). Examining a range of psychosocial problems of breast cancer patients using the CARES (Cancer Rehabilitation Evaluation System) trait scale, Avis et al (2004) reported that

"applicable" problems mentioned by a group of women surveyed included a lack of sexual interest and sexual dysfunction following mastectomy, which was related to the post-mastectomy body-image. Other authors have also debated the effect that mastectomy can have upon a woman's sexuality, albeit from a more qualitative perspective. Taylor was 43 years old when she underwent a mastectomy following a diagnosis of DCIS in her right breast. She decided to have a prophylactic mastectomy in her contralateral breast. She recalled:

> I had been so afraid of the operation; I wasn't sure if I would still look good. Would my breasts look natural again? Would my man still want me and what about sex? – would it still be exciting and passionate? Or would I look and feel like a freak?
>
> Taylor, cited in Farrell Yelland, 2000:68.

Taylor's account stresses women's concerns in relation to the reactions to their mastectomy, both for themselves and their partners. The quotation emphasises women's anxiety that their breasts may no longer look good or "natural", and that they might "feel like a freak". These fears will have a negative influence upon women's perceptions of their femininity and sexuality, and lead them to believe that their post-mastectomy appearance may cause offence (Harwood and O'Connor, 1994). Describing the impact that her appearance of her post-mastectomy breasts has upon her husband's perception of her sexuality and sexual attractiveness, one of Lloyd et al's respondents stated:

> when [my husband] saw it, he was like, he just couldn't believe it. You know, he sort of said 'oh my God, what have you done, it's awful, it looks terrible', blah blah.
>
> Unnamed respondent, cited in Lloyd et al, 2000:479.

In contrast to such a negative experience, other women have reported that partners have reacted more positively to their post-mastectomy appearance. Kasper referred to Carol, whose husband was reported to have said, "I'll love you anyway, it doesn't matter" (1995:211), and Kaplan (1992) argued that men 'tune out' their partner's 'missing' body part. Despite such reassurances, women continued to feel "ugly and lopsided following their mastectomy" (Berger and Bostwick, 1998:141). Moreover, for most women, "femininity [is] a core issue and…..their 'mastectomy appearance' deprived them of feeling fully female" (Berger and Bostwick, 1998:141). For example,

Fallowfield and Clark discussed a respondent who stated, “I know you’ll think me a silly vain old thing, but quite honestly, since the operation, I just don’t feel like a woman anymore” (1991:64). Yet for others, a mastectomy did not lessen perceptions of their femininity:

> a woman’s response need not be the loss of her sense of womanliness, nor of her femininity either, despite any male fixation on the breasts as a mark of beauty.
>
> Hoge Thompson cited in Lifshitz, 1988:xxi.

Throughout this chapter, I have shown that the value and worth placed upon women’s breasts have been socially constructed. I have argued that there is nothing intrinsic in women’s breasts that can denote the extent of her womanliness, femininity or sexuality. Nevertheless, something happens which consequently results in women undergoing mastectomy questioning their appearance. Lorde suggested that in a society “where the superficial is supreme, the idea that a woman can be beautiful and one-breasted is considered depraved, or at best, bizarre” (1980:65). Lorde’s criticism emphasises the superficial values that ‘society’ can place upon body parts and appearance. Other authors have been less vociferous in their condemnation, but have implied the same line of thinking (Hallowell, 2000; Potts, 2000). Due to the socially constructed nature of what is an acceptable appearance, we are told that it is unacceptable to be breastless, yet for some women with breast cancer, or at-risk of breast cancer, being breastless may save their lives.

In an account of her risk experience and decision-making, Lewis described her reaction to the recommendation that she should undergo prophylactic surgery:

> I was deemed at very high risk. [The breast cancer nurse] came to my house and advised me to have a double mastectomy. She also suggested that I have my ovaries removed as well, as the faulty gene that causes breast cancer increases your risk of developing ovarian cancer too. At first, I refused point blank. I didn’t have cancer, so why should I put myself through all of that pain? And why should I remove everything that makes me a woman?
>
> Lewis, 2001:167.

Lewis’ account is analogous to many others published and also to those I discuss in chapter eight. Her narrative illustrates that her initial reaction to prophylactic surgery,

that she did not have cancer and so why should she have surgery, experience pain and suffering and lose everything that made her a woman, quickly became trivial when she came to terms with the threat of cancer.

Accounts published by breast cancer 'survivors' often reflect this opposing stance. Within such accounts, breast cancer is not illustrated in terms of body-image or femininity. Rather, as suggested earlier in the chapter, breast cancer is described as a matter of life or death. By overly concentrating on notions such as body-image and sexuality there is a risk that one is allowed to forget that a woman can lead a fulfilling life despite being 'breast-less'. Hallowell examined women's reactions to breast reconstruction as either reconstructing the body or reconstructing the woman, and argued that when faced with the threat of breast cancer, anxieties about the loss of femininity became less significant:

> my life is more precious to me, you know, than part of my femininity or sexuality, which I can learn to have in other ways.
>
> Patricia, cited in Hallowell, 2000:173.

Similar accounts see women explaining, "I was worried about my life - my breast doesn't count that much" (Hobler Kahane, 1999:217) and "it became totally irrelevant that I had one breast. I realised femininity is nothing to do with how many breasts you have. It's in your head" (Vicky, cited in Riley-Jones, 2001:61). Bredin sounded an important note of caution, commenting:

> researchers' assumptions that breast loss is the primary concern for women facing breast cancer may only serve to detract from the gravity of facing a life-threatening illness.
>
> Bredin, 1999:1114.

Consequently, so not to belittle the real threat of breast cancer, it is important to remember that "breast cancer is not really about breasts, its about life and death. You've got a life threatening illness, you've got to have horrible treatment, but the breasts are irrelevant" (Picardie, cited in Potts, 2000:55).

Many of the accounts that I have discussed in this chapter, were given by, or have described women diagnosed with breast cancer. However, as I show in chapter eight, there seems to be little difference between these accounts and those given by women at-risk of HBOC; the perceived threat to, and loss of their breasts appears to be just as great when women are at-risk of breast cancer.

ii. Oophorectomy.

In chapter one I discussed the relatively low five-year survival rate for ovarian cancer. Consequently, ovarian cancer has been described as the "deadliest" of all the gynaecological cancers (Ferrell et al, 2003:647), as the tumour is concealed and is non-palpable (Hallowell and Lawton, 2002). Women at-risk of HBOC are therefore urged to have a prophylactic oophorectomy upon the completion of their childbearing.

The ovaries may be perceived as symbolic markers of 'womanhood', because of their role as a reproductive organ. However, much of the existing literature on the prophylactic removal of the ovaries depicts them as a body part that can be removed without causing extensive harm (Hallowell et al, 2001; Hallowell and Lawton, 2002). Hallowell and Lawton discussed the 'surplus' nature of the ovaries, in relation to women's justifications for their decision to have a prophylactic oophorectomy. For example, they referred to Vicky, who stated, "with ovarian cancer being a silent cancer, and knowing that I'd completed my family, um, I thought, well, have them out, they're no good to me anymore" (cited in Hallowell and Lawton, 2002:429). Similarly, whilst comparing her ovaries to another body-part which was superfluous, Abby reasoned "to me, they're just like an appendix" (cited in Hallowell and Lawton, 2002:430). Thus, the impact of the surgical choices available to women at-risk of HBOC have vast differences in how women react to them and perceive their femininity following the procedure. For example, Metcalfe et al argued, "surgical removal of the breasts has a greater impact on a woman's self-image than oophorectomy" (2000:872). Mastectomies evoke a different social reaction to oophorectomies. Hallowell summarised these differences, and reasoned:

> the oophorectomised woman still looks like a woman despite the fact that her hormones are compromised and her reproductive life is effectively curtailed. Mastectomy, on the other hand, [is] regarded as more threatening because it results in perceptible changes to the body. It [is] seen as a compromise to gender and personal identity in a more profound manner because it is unavoidably public – the mastectomised woman may look different.
>
> Hallowell, 1998:272.

As Hallowell's comparison illustrates, the loss of the ovaries is not considered to affect quality of life to the same extent as prophylactic mastectomy (Wagner et al, 2000). Many authors have described how mastectomised women perceive that their femininity has been compromised in ways that oophorectomised women do not (Hallowell, 1998; Potts, 2000). Summarising this line of argument, Berchuck et al proposed:

> most women do not view removal of ovaries as cosmetically mutilating, and oophorectomy causes only modest changes in body-image and self-esteem.
>
> Berchuck et al, 1999:2521.

However, whilst an oophorectomy does not result in any significant body changes compared to a mastectomy, it does induce or cause physiological alterations in women's bodies. Such side effects of oophorectomy include a premature menopause, premature ageing, coronary heart disease and osteoporosis (Fry et al, 2001; Hallowell and Lawton, 2002). Moreover, women may experience "depression, fatigue, hot flushes and urinary symptoms", lower body-image satisfaction, reduction in their libido, the frequency of coitus, and the level of sexual arousal (Fry et al, 2001:232). Thus unlike that experienced with mastectomy, the negative impact of surgery is mostly concealed, yet women undergoing oophorectomy also face threats to their quality of life.

2.5. The effect of the medicalisation and geneticisation of women's bodies.

Feminist medical sociologists have become increasingly concerned with the medicalisation of women's bodies (for example, Ehrenreich and English, 1979; Oakley, 1980; Corea, 1985; Daly, 1990; Lupton, 1994). Such a stance can be illustrated with the view that 'natural' life events including childbirth, menstruation, reproduction, menopause and issues such as body and weight management, and fertility management have become managed by the medical profession.

The medicalisation thesis argues that medical meanings and medical management have been projected onto 'normal' life events, or social conditions (Conrad, 1992). Becker and Nachtigall describe how medicalisation has enabled human experiences, behaviours and conditions to be redefined as medical problems and as such, can be controlled or eliminated (Riessman, 1983). As a result of this move, greater numbers of people have fallen under the "clinical gaze", which has "far reaching consequences" for those involved (Riessman, 1983:3).

Riessman (1983) attacked the medicalisation of "a plethora of female conditions", and the notion that biological events should have medical solutions are applied to them. To take just one example of the medicalisation of a previously biological (and non-medical) event, the menopause, it is possible to illustrate how a normal life event, has become medicalised in contemporary society. Although the menopause results in a physiological change in women's bodies, it was traditionally considered a life event; now, according to Griffiths (1999), it is treated as a hormone deficiency disease in need of treatment.

Examples such as that of the medicalisation of menopause demonstrate the social nature of illness. The menopause has become constructed as a disease. Likewise, the management of childbirth also demonstrates how a 'natural' life event has become supervised by the medical profession, who view it as "a potentially diseased condition" (Treichler, 1990:119). Feminist medical sociologists, including Oakley (1980) and Treichler (1990) have proposed that the once normal experience of childbirth is now perceived to be 'risky' and in need of highly technical medical intervention. Treichler argued that, "pregnancy and childbirth can only be diagnosed as 'normal' retrospectively, when both mother and infant are discharged in good health" (1990:117). Feminist medical sociologists have argued that the social construction of disease benefits the medical profession, who rely upon the notion that they alone can manage disease because of their superior knowledge and authority about the body (Oinas, 1998). However, there has been increasing support for the idea that medicalisation may also advantage patients (Becker and Nachtigill, 1992; Wiles and Higgins, 1996).

Griffiths argued that medicalisation has:

> encourage[d] both doctors and women to view their current health status in terms of their risk of future ill health and so encourages medicalisation of the future.
>
> Griffiths, 1999:470.

Consequently, the medicalisation thesis has moved beyond 'medicalising' current events, to 'medicalising' the future or one's future risk of disease. Meltzer and Zimmern referred to, "premature medicalisation – of attaching the 'disease' label before it has been established that prevention or treatment is clearly beneficial" (2002:863). The medicalisation of HBOC offers such an example. HBOC has become labelled as a disease although no pathology exists, and as I discussed in chapter one, is treated medically despite there being no consensus that prophylactic surgery will prevent cancer from developing.

The development of genetic medicine and the ability to treat someone who is not yet diseased with identical procedures as a 'diseased' patient would face, has extended the work previously carried out by advocates of the medicalisation thesis. Not only are women's bodies medicalised, they are now geneticised (Lippman, 1991, 1992, 1998; Hallowell, 2000). The discovery of the BRCA genes has enabled the medical management of women's 'risky' bodies to be amplified.

Geneticisation is the term given to describe:

> an ongoing process by which differences between individuals are reduced to their DNA codes, with most disorders, behaviours and physiological variations defined, at least in part, as genetic in origin. It refers as well to the process by which interventions employing genetic technologies are adopted to manage problems of health.
>
> Lippman, 1991:19.

This concentration upon a person's DNA codes as a precursor to their future health state, has led to a subtle reformation of the concepts of health and disease. Lippman (1998) argued that geneticisation has inappropriately led to some healthy women becoming labelled as patients.

However, being labelled as at-risk of HBOC and carrying a BRCA1 or BRCA2 gene is not the same as having cancer. Yet despite the lack of disease or cancerous cells, "it is commonly interpreted as such" (Sherwin and Simpson, 1999:124). Moreover, although between 15%-60% of women carrying either gene will never develop hereditary cancer, this has been relatively ignored. Geneticisation focuses our attention on "on what is wrong internally in the individual that she should develop the disease" (Sherwin and Simpson, 1999:124). As such, geneticisation feeds upon women's anxieties about developing breast and ovarian cancer, and builds upon medical opinion that contends that the surgical risk management options are the only viable manner in which women can reduce their risk of developing HBOC.

Consequently, prophylactic mastectomies, "a once unthinkable step" (Thompson, 1994:38) are now routinely offered to women found to carry a positive BRCA1 or BRCA2 genetic mutation. Despite their popularity, prophylactic mastectomies represent a controversial and drastic option in the attempt to prevent breast cancer (Houn et al, 1995; Stefanek et al, 1999).

Bilateral prophylactic mastectomies and prophylactic oophorectomies can reduce the anxiety and worry which is linked to waiting for the cancer to possibly manifest, and the decision to have prophylactic surgery is based very much on distinguishing between life and death; Lerner suggested that "losing a breast became a type of quid pro quo for getting life" (2001b:188; original emphasis). As I discussed in the previous chapter, mastectomy involves the surgical removal of the diseased, or potentially diseased breast tissue. Medical research suggests that the "drastic option of amputating healthy breasts" (Jones cited in Kasper and Ferguson, 2000:128) and undergoing a "bilateral prophylactic mastectomy may significantly reduce the development of breast cancer in women at increased risk" (Bebbington Hatcher et al, 2001:1). Therefore, for women at-risk, breast amputation offers a possibility of controlling what they see as their out-of-control bodies (Potts, 2000).

However, as I reported in chapter one, whilst performing a prophylactic mastectomy, the nipple-areolar complex, the surrounding skin and underlying breast tissue can be removed, yet a minimal residual amount of breast tissue remains, and it is widely reported that breast cancer can still develop following prophylactic mastectomy

(Bucholtz et al, 2001; Hartmann et al, 1999). Although prophylactic surgery offers a means of controlling breast cancer associated with HBOC, it is not 100% effective. Cancer may develop, return at the site of the surgery, or elsewhere in the form of metastases (Hallowell, 1998; Hartmann et al, 1999; Fry et al, 2001). Furthermore, following reconstructive breast surgery, the chest wall can be difficult to examine, and problems with mammography have been reported (Blamey et al, 2000; Lucassen et al, 2001). As such, should a cancer develop, diagnosis can be problematic (Wilkinson and Kitzinger, 1993).

In addition to the debatable efficacy of surgery in relation to its ability to reduce, or stop cancer from developing, the surgical procedures are not without risks themselves. Prophylactic surgery, whilst beneficial in that it reduces the risk of disease developing, involves healthy bodies falling under the medical gaze and being subjected to invasive surgical procedures. Women undergo prophylactic mastectomy and oophorectomy to reduce their risk of illness and disease, yet surgery may have iatrogenic and psychological consequences. Like any invasive surgery, there are risks associated with anaesthesia, while complications can arise post-operatively with infections, ruptured silicone implants and scars, in addition to problems involved in the premature onset of the menopause, such as osteoporosis and taking HRT when you already have a heightened risk of breast cancer (Edelman, 1994; Rebbeck et al, 2002). Further iatrogenic consequences can include distorted scarring, pain, numbness of skin, muscular tension and lymphodema (Bredin, 1999). Moreover, as I discussed earlier in the chapter, prophylactic surgery can have negative psychological, social and emotional effects upon a woman's self esteem, her body-image, sexuality and perceptions of femininity. Spousal relationships may also be harmed. Consequently, Watson et al described "the benefits of available risk management options [as] equivocal" (1999:868).

In an attempt to lessen the negative psychological consequences that prophylactic mastectomy may have on their perceptions of their body-image, women frequently choose to have their mastectomised breasts reconstructed. Breast reconstruction:

> involves taking new skin and tissue from another part of a woman's body and keeping the blood vessels intact, [so that] these [can be] swung around to form a mound on the site of the original breast. Alternatively, the breast tissue can be substituted by a plastic sac which is laced under the skin and then filled with fluid until the 'correct' size is reached.
>
> Wilkinson and Kitzinger, 1993:231.

Currently the two most frequently used reconstruction techniques are the transverse rectus abdominis musculocutaneous (TRAM) flap procedure and implants filled with a saline solution (see chapter eight, pages 207-208 for pictures of the aesthetic outcomes of these techniques). The TRAM procedure involves the use of a skin graft, usually taken from the stomach, but can be donated from the buttocks or the back, which is used to build a new breast. The procedure is more invasive than reconstruction using saline implants and can result in scarring and post-operative infection. In contrast, reconstruction using saline implants creates little scarring, although problems can arise with the body rejecting the implants and the implants calcifying and hardening (Renwick, 1996).

Reconstructive surgery enables women to overcome negative body-images, abnormal body structures and poorly functioning bodies (Davis, 1995; Sullivan, 2001). Kasper described how "procedures are available to restore body-image and the accompanying sexuality and femininity which, to many, can be as important as life itself (1995:199). However, such procedures have been criticised. Lorde (1996) attacked the practice of reconstructive surgery as allowing women to 'pretend' that their breasts had not been removed, or that they had not been at-risk of a life threatening disease. Following reconstructive surgery, the resulting body-image is shaped by the socially constructed, medicalised perception of 'normality': what a 'normal' women looks like. Consequently, prior to undergoing reconstructive surgery, "women are instructed that their bodies are unacceptable" (Davis, 1995:3). Whilst Little suggested that cosmetic surgery "gratifies a patient's desire to meet the norm" (1998:172), and Bordo (1998) argued that it should be recognised as a tool for empowerment, Davis maintained that "the patient may simply find that the surgery does not bring the relief she had expected and is confronted with the same unhappiness she had before" (1993:26). Whilst the breast or ovaries have been removed and possibly replaced, the threat of disease may still linger.

Given the cultural significance bestowed on women's breasted appearance, it is no surprise that post-mastectomy, many women feel required to re-negotiate or reappraise their identity (Hallowell and Lawton, 2002). Moreover, prophylactic surgery necessitates a further re-negotiation of identity; women are no longer identified as at-risk, as they have taken all available measures to significantly reduce the risk of cancer developing. As I have shown in this chapter, prophylactic surgery may result in adverse consequences in terms of women's perceptions of their femininity, sexuality and body-image. Whilst reconstructive techniques may counteract some of these feelings in relation to breast loss, there is no comparable procedure to balance the effects of oophorectomy.

Chapter Three. The Sociology of the Doctor-Patient Relationship.

> What makes the doctor-patient relationship so complex? Well, for one thing, the doctor has more power than the patient, the doctor has more knowledge about the particular subject to hand than the patient, the patient is understandably anxious, the doctor has more responsibility…..
>
> Korsch and Harding, 1997:3.

The doctor-patient relationship has been a popular area of study within medical sociology since the 1950s. Within a vast body of literature, some of the most renowned studies include Parsons' (1951) investigation of the sick role, Freidson's (1970) examination of the profession of medicine and Zola's (1973) assessment of the triggers that prompted people to seek medical intervention. Within the UK, examples of medical sociological enquiry into the doctor-patient relationship have focused upon encounters between patients and their general practitioners (Stimson and Webb, 1975; Byrne and Long, 1976; Heath, 1992), encounters between the doctor and the patient in hospital settings including the oncology and paediatric wards (McIntosh, 1977; Strong, 1979), the diabetes clinic (Silverman, 1987) and HIV/AIDS counselling sessions (Silverman, 1997). Moreover, the doctor-patient relationship has been used as a site of research from which topics such as patient satisfaction with the consultation (Locker and Dunt, 1978), compliance with prescribed therapies and medications (Britten et al, 2000) and patient-centredness (Barry et al, 2000) have been focused on.

As this brief introduction has demonstrated, the doctor-patient relationship has been a popular subject for researchers. Consequently in the space available, it is not possible to review all of the existing literature. Therefore, the aim of this chapter is to provide an overview of the existing work. In this chapter, I address:

3.1. The history of the doctor-patient relationship.

3.2. Popular models of decision-making within the doctor-patient encounter.

3.1. The history of the doctor-patient relationship.

The development of modern, Western medical practice reflects the changing gazes and discourses of medical interaction and illustrates how over time, the focus of medical inquiry has shifted from the patient to the cell. In lay terms, the history of the doctor-patient relationship can be demonstrated in relation to the changing methods by which the underlying medical problem is investigated: from the patient's subjective illness experience, to the investigation of pathology as scientific advances were made.

i. Bedside medicine.

Bedside medicine, prominent in the late 17th century, was recognisable for its "conscious human totality" (Jewson, 1976:227). It depended greatly on the patronage system, whereby the moneyed could purchase the skills and time of a physician. However, not only did the sick man (sic) buy the skills of the physician, but he bought the services of a physician who shared his own medical theories about the causation of disease and its appropriate treatment or cure. Consequently, patients shaped the ensuing interaction because of their powerful market position. In order to earn their living, doctors were dependent upon their patrons, and as such deferred to their ideas about the causation of illness and disease so that they would maintain their custom. Such medical practice concentrated on the person and their evaluation of the symptoms or subjective illness experience, which allowed the physician to diagnose the ailment. As a result, the model of bedside medicine might be perceived as an early example of a patient-centred consultation, as the patron ensured that "his own needs and the manner in which those needs were to be met" were addressed by the doctor (Waddington, 1973:213).

ii. Hospital medicine.

The development of hospital medicine at the beginning of the 19th century challenged the existing model of bedside medicine (Davey and Seale, 1994). The rise of hospital medicine was linked to the professionalisation of medicine, gained through formalised training and education (Armstrong, 1987). Specialist skills and education, available to a select few, led to the institutionalisation of the medical 'object': the patient. Prior to this, diagnosis had been dependent upon the patient telling their symptom story to the

physician, who then performed simple techniques aimed at ameliorating the symptoms. However, with the advent of hospital medicine:

> medical investigators concentrated upon the accurate diagnosis and classification of cases rather than upon the prognosis and therapy of symptom complexes. The sick-man became a collection of synchronised organs, each with a specialised function.
>
> Jewson, 1976:229.

The gaze of the doctor fell upon a disease rather than upon the individual. The medical model now focused on the internal organic events occurring within the body, which were diagnosed through physical examinations. Subsequently, pathology, "the study of manifestations of disease in the body" (Webster, 1994:40) became the dominant focus of medical practice. Correspondingly:

> diagnoses were founded upon the physical examination of observable organic structures rather then verbal analysis of subjectively defined sensations and feelings.
>
> Jewson, 1976:229-230.

Waddington (1973) explained that the development of the hospital and examination techniques reduced the sick-man to a patient; hospital medicine was thus an early example of a diseased-centred medical approach. The doctor replaced the patient as the central party in the doctor-patient encounter, leading Armstrong to describe the "emancipation of the doctor from his patrons" (1979:1). The reliance upon new medical specialisms rather than upon patients' subjective symptom narratives indicates that the existence of pathology became the dominant cause of disease. Hospital medicine ignored patients' needs and desires about treatment (Waddington, 1973), favouring the doctor's examination of the pathological lesion.

iii. Laboratory or clinical medicine.

As scientific knowledge developed hospital medicine was surpassed by laboratory medicine in mid-19th century. Laboratory medicine, also labelled as clinical medicine, focused upon individual cells, following the recognition that if "the cell was the fundamental unit of life, then it must also be the locus of disease" (Jewson, 1976:230).

At this stage in the historical progression of the doctor-patient relationship, the patient was removed "from the medical investigators field of saliency altogether" (Jewson, 1976:237). The patient was no longer considered integral to the consultation; they did not need to explain their symptoms, or present their body for diagnostic examinations. Pathology samples were removed from the patient and analysed far away from the medical encounter. Jewson summarised this shift, and explained:

> the eclipse of bedside medicine by first hospital and then laboratory medicines represented a shift away from a person orientated toward an object orientated cosmology.
>
> Jewson, 1976:232.

Foucault (1973) added to this summation, and argued that whilst 18th century medicine was based on the historical knowledge of the patient's symptoms, 19th century medicine was based on the doctor's philosophical knowledge of the origins of disease. However, although the disappearance of the sick-man was fundamentally due to the scientific, pathological and laboratory based innovations of the 19th century, it was also aided by the changing relationship between the doctor and the patient because of the doctor's ability to detach himself from the demands of his patron (Jewson, 1976). The subsequent roles of the doctor and the patient following the patronage system of bedside medicine have enabled the doctor to play a greater part in the consultation. Comparably, the patient has seen their level of participation increasingly reduced.

iv. The return of the sick man?

Many of the traditional representations of the doctor-patient relationship portray "two distinct personalities, but still involve the objectification of the patient's body" (Brackenbury, cited in Armstrong, 1982:113). Armstrong suggested that within the medical relationship the patient, "is construed as a passive object, expecting from the doctor certain qualities – knowledge, skill, carefulness, judgement, sympathy, understanding, moral character, and ethical conduct" (1982:113). However, Balint (1957) recommended a different approach, investigating illness via a biographical method. Within biographical medicine, illness is located within its social context. Although still objectifying the patient as a medical object, biographical medicine

focuses holistically upon the patient opposed to just a specific pathological lesion. Consequently, Armstrong argued:

> biographical medicine transposed symptoms from their status as relatively weak indicators of underlying pathology to the part of the medical problem itself, and thereby transformed the patient from a passive receptacle of organic pathology to the centre of the medical problematic.
>
> Armstrong, 1979:5.

The biographical model of medical interaction reintroduced the sick-man, and once again gave the patient a role within the consultation. Hence, it can be argued that the doctor-patient relationship again changed from one involving distinct active-passive roles, to one where the patient has become more important (Balint, 1957). Recently, health care has been characterised by a move towards greater partnership between the doctor and the patient (Charles et al, 1998). This development has reinforced the shift from a disease-centred model of medical enquiry, in which "there was a disembodied, disinterested eye, contemplating a depersonalised, disintegrated body" (Gothill and Armstrong, 1999:10) to a person or patient-centred approach.

v. Surveillance medicine.

Modern medical techniques, introduced in the 18th century reinforced the disciplinary power of the medical profession over the patient (Foucault, 1973). Instruments such as the stethoscope enabled the doctor to assert control over the patient, who was asked to remain silent whilst the doctor listened to their chest. Such an example demonstrates how the body became an object, and was considered to be "something docile, useable and transformable which justified further surveillance" (Armstrong, 1987:110).

Illness has come to be viewed as a community issue, rather than an individualised phenomenon, which has allowed greater medical surveillance and medicalisation of the healthy. This stance has led to a re-classification of health and illness. Once binary opposites, with the rise of genetic medicine the population is now considered to be potentially diseased and we are viewed as future patients. Therefore, it is possible to illustrate how the journey from the sick-man to the pathology and from the pathology to the lesion, has now returned to the patient. The rise of genetic medicine has

subsequently extended the gaze, or scope of the surveillance, or disciplinary power that the medical profession has over patients. However, although the advent of genetics has led the medical gaze to fall on the person again, it is matched by the gaze also focusing on the cell. For example, Armstrong et al argued, "genetic disease can claim to be the ultimate pathological lesion" (1998:1658). Therefore, although the patient is important within the genetics cosmology, so too is her DNA.

The preceding discussion has illustrated that the history of medicine is neither linear nor simple, but transitional and accumulative (Davey and Seale, 1994). This finding supports Foucault's statement that "the exact superposition of the 'body' of the disease and the body of the sick-man is no more than a historical, temporary datum" (1973:3). Each conceptualisation of the doctor-patient relationship is no more than a product of the encounter in which it occurs. Many of the historical models of the doctor-patient relationship have illustrated that an asymmetry exists between the doctor and the patient. The doctor has been depicted as the medical expert, knowledgeable and skilful. Comparably, other than in the bedside and biographical models, the patient has been characterised as a passive member of the consultation. In the remainder of this chapter, I extend the focus on the roles of the doctor and the patient, and discuss these in relation to clinical decision-making.

3.2. Popular models of decision-making in the doctor-patient relationship.

In addition to the more historical models discussed in the previous section of the chapter, many other typifications of the doctor-patient relationship have been offered in the medical sociological literature since the 1950s, including the activity-passivity model, the guidance-cooperation model, and the mutual participation model (Szasz and Hollender, 1956) and paternal model, the informative model, the interpretive model and the deliberative model (Emanuel and Emanuel, 1992). However, in the space permitted in this chapter, I have chosen to review three of the most encompassing models of doctor-patient interaction that describe the roles that each party play in treatment decision-making.

i. The disease-centred model of doctor-patient interaction.

The most renowned medical sociological account of the doctor-patient relationship is Parsons' (1951) discussion of the sick role. Based on his observations of medical encounters during the 1930s and 1940s, Parsons discussed how medical practice was a social mechanism that coped "with the disturbances to the 'health' of the individual, with 'illness' or 'disease' (1951:429), via the use of institutionalised roles and mutual obligations. The doctor had a professional obligation towards the welfare of his patient; the patient had an obligation to get well.

To successfully inhabit the doctor role, the doctor is expected to apply his skills and knowledge in addressing the illness, carry out these actions according to the best interests of the patient, rather than themselves, be objective, emotionally detached and be guided by professional rules. For the sick person to inhabit the patient role they must adhere to the following obligations and rules; they must want to return to full health as quickly as possible, seek professional advice and co-operate with the doctor. In return, whilst unwell, the patient will be permitted to shed some of their normal responsibilities, as "illness incapacitates for the effective performance of social roles" (Parsons, 1951:430) and will require care to return them to a state of health. As such, the doctor is a gatekeeper to the successful entry into the sick role and a state of dependency (Murphy and Dingwall, 2003). The sick role obligations stipulate that the patient seeks technically competent help in order to facilitate a return to health. The doctor is the only party competent enough to provide their service. Thus, the patient is dependent upon the doctor. However, the doctor also has an obligation to society. He is the gatekeeper to the state of dependency, and it is a functional necessity (Maynard, 1991) that he only allows the legitimately sick to inhabit the sick role and abandon their social responsibilities.

Parsons used the sick role not only to demonstrate the responsibilities, roles and obligations of the doctor and the patient within the illness experience, but also to illustrate how any deviant act that poses a threat to societal stability is dealt with. Parsons considered that illness might be a way of evading social responsibilities. Consequently, "both the sick role and that of the physician assume significance as

mechanisms of social control" (Parsons, 1951:477), because of their "latent functions with respects to the motivational balance of the social system" (Parsons, 1951:476).

Parsons' configuration of the doctor-patient relationship is disease-centred, and is characterised by its paternalism. Such a model demonstrates an asymmetry between the positions, statuses and decision-making roles of the doctor and the patient. Parsons described the patient as "helpless…[with a] lack of technical competence, and emotional disturbance [which] makes him a peculiar vulnerable object for exploitation" (1951:445). Contrastingly, "the role of the physician centres on his responsibility for the welfare of the patient in the sense of facilitating his recovery from illness to the best of the physician's ability" (Parsons, 1951:447). In Parsons' terms then, the asymmetry between the doctor and the patient developed because the patient was a helpless, incompetent and vulnerable recipient of the doctor's knowledge. The rewards of the consultation saw the doctor promote his knowledge, expertise and professional status, whilst patient received the treatment required to alleviate her symptoms.

Disease-centred relationships such as that Parsons discussed, involve a one-way exchange of information, from the doctor to the patient (Charles et al, 1999). The doctor and the patient do not interact with one another (Szasz and Hollender, 1956). The doctor has an effect upon the patient. The doctor is active and in control of the consultation, thus rendering the patient inactive and unable to participate to the same extent. Consequently, the patient plays little or no part in deciding which treatment regime to follow, and the doctor is in "absolute control of the situation" (Szasz and Hollender, 1956:587). The doctor's role is to diagnose the patient's disease, decide upon treatment and return the patient to full health. The patient's role is to play no active part in their diagnosis or return to health.

For some patients, a model with such paternalistic characteristics has inherent advantages. While doctors make what they consider to be the best decision for the patient, patients and their families are spared from the anxiety of having to make difficult and possibly ill-informed choices. However, the assumption that the doctor will know 'what is best' for the patient can be questioned. It is no longer certain that doctors and patients espouse similar values and views concerning what is going to be of value or the best treatment for them. Therefore, for some patients, there are "obvious

problems with excessive paternalism" (Quill and Brody, 1996:2). Conflict between the doctor and the patient can occur because of the opposing standpoints, experiences and expectations of each party. Freidson (1970) argued that such a clash of perspectives arose due to a structural divide between the professional world of the doctor and the lay world of the patient. He stated:

> given the two viewpoints of the two worlds, lay and professional, in interaction, they can never be wholly synonymous.
>
> Freidson, 1970:321.

The different roles and obligations of the doctor and the patient mean that some form of clash is inevitable. One way in which the disparity in participation levels of the doctor and the patient might be reduced, is with a more patient-centred approach to the consultation.

ii. The patient-centred model of doctor-patient interaction.

> The doctor-patient relationship has changed dramatically during the recent years, the doctor becoming less authoritative and the patient becoming more autonomous.
>
> Lagerløv et al, 1998:88.

Laine and Davidoff have suggested that although "patient's welfare has always been the ultimate driving force in medicine, clinicians have historically pursued patients welfare via a predominantly provider-centred model of care" (1996:152). Nevertheless, in recent years, the patient-centred model of doctor-patient interaction has become increasingly popular (Stewart et al, 1995; Mead and Bower, 2000; Stewart and Brown, 2001).

Bensing et al (2000) described patient-centred medicine as the new paradigm for the 21st century. However, although Stewart (2001) argued that patient-centred medical practice was becoming widely advocated and employed, as a concept 'patient-centredness' is poorly understood and many of its arguments are misunderstood and overstated (Stewart et al, 2001). Characteristics of a patient-centred approach can include: effective listening, open questioning, statements which affirm and reflect back, summarising (Woodcock et al, 1999), eliciting and discussing patients' beliefs, and patients taking control of the consultation and management of their disease (Michie et

al, 2003). Yet patient-centred medicine is most often known for what it is not; patient-centred medicine is neither technology-centred, doctor-centred, hospital-centred nor disease-centred (Stewart, 2001). Rather, patient-centred care means, "taking into account the patient's desire for information and for sharing decision-making and responding appropriately" (Stewart, 2001:445). van Dulmen described patient-centred care as a model of practice which allows "patients more control of the medical visit" (2003:195). Thus, health care can be considered patient-centred when "attempts are being made to activate the patient to take some control….or when patients' thoughts and feelings are elicited and discussed" (van Dulmen, 2003:195). Byrne and Long (1976) found that patient-centred medicine could be characterised by a less authoritative approach, in which patients were encouraged to participate in the consultation, and doctors actively appeared to be listening to them. The term is thus ambiguous, but in its simplest form can be defined as one where the doctor takes a lesser role, allowing the patient to be more active.

However, this action of 'allowing' or 'enabling' the patient to be more participative in the consultation illustrates that the relationship between the doctor and the patient remains asymmetrical. Rather than the patient actively asserting themselves and reducing the power imbalance, the doctor actively constructs and manages the situation so that the patient is able to participate to a greater extent. Nonetheless, the doctor remains in overall control.

The patient-centred approach has been shown to have a positive effect upon patients' adherence to treatment regimes (Kinmonth et al, 1998), management of disease (Herbert and Vissner, 1996) and improved therapeutic outcomes (Greenfield et al, 1988; Michie et al, 2003). Yet the approach can be problematic for doctors, who report that the patient-centred approach is too time consuming, as it takes extra time to elicit patients' concerns in addition to performing the required medical checks (Woodcock et al, 1999). Despite doctors' concerns, "a shift from the traditional medical model towards a patient participation, patient-centred, sharing, patient empowerment model is advocated, as this is regarded as necessary to meet modern quality standards in the…..21st century" (van Dam et al, 2003:21).

In a society where chronic illness is becoming more frequent and patients are better educated about their illnesses, it is likely that patients will have more experience and greater knowledge of their condition than many doctors (Macintyre and Oldman, 1975; Kaplan et al, 1989). Consequently, the consultation becomes "a critical intersection for information exchange, decision-making and motivation" (Thorne et al, 2004:299). Charles et al argued that patient-centred medicine recognises that "patients are not empty vessels. They come to the medical encounter with their own beliefs, values, fears, illness experiences and increasingly, information about various treatment options" (1999:655). Bloor (2002) extended the argument for the patient to be recognised as an expert. Referring to the patient as "Citizen Science" (Bloor, 2002:22), Bloor argued that patients may now have the technical knowledge or expertise to be able to participate on a more equal level to that of the doctor. In illustrating such this, Bloor (2002) referred to a body-builder who reportedly took cycles of steroids, and illustrated how patients can understand and use technical medical jargon:

> right now I'm doing a 9-week building cycle. Do you want to know what I'm taking? Deca for 3 weeks, Heptylate for three weeks, Testoviron for 3 weeks. And then the last 4 weeks – then I'll stack them with Pronabol.
>
> Unnamed respondent, cited in Bloor, 2002:23.

Bloor (2002) reasoned that almost every patient, except an unconscious one, can comment upon their illness and thus participate in the consultation to some extent. However, this does not mean that the consultation is an example of a shared relationship between the doctor and the patient. Rather, he suggested:

> the patient-centred consultation is artfully contrived, bounded and orchestrated by the practitioner.
>
> Bloor, 2002:33.

Whilst shared, informed and patient-centred models of the doctor-patient interaction can be regarded as a reaction to traditional, paternalistic, doctor-centred medicine, is it realistic to see the doctor and the patient as equal partners? Bloor's quotation emphasised that there is an inherent information and power imbalance in the relationship, due to the social closure of the medical profession and the greater status, knowledge and expertise of doctors.

A central issue within contemporary medical practice has been "respect for the patient as a person" (Quill and Brody, 1996:5). Many patients expect to be involved in their treatment processes, although a large number of patients still want the clinical team to take charge. Guadagnoli and Ward summarised this:

> although not all patients will want to take control of their medical care, it is still important that their concerns, desires and values be incorporated into decisions about their care.
>
> Guadagnoli and Ward, 1998:329.

Furthermore, Bensing et al (2000) reported that not all patients will demand the same from their relationship with the doctor. Thus, the medical relationship needs to be capable of reacting to the needs of each individual patient, regardless of what these needs are.

iii. The collaborative model of doctor-patient interaction.

> Both persons are 'active' in that they contribute to the relationship and what ensues from it.
>
> Szasz and Hollender, 1956:587.

In the collaborative model of doctor-patient interaction, each party negotiates the consultation space in order to address their own needs. In order for the doctor to be able to react to the individual need and requirements of each patient, the patient must be able to inform the doctor of their wishes. Consequently, the ensuing consultation is characterised by the "joint participation of the two persons involved" (Szasz and Hollender, 1956:586). Thus, in Szasz and Hollender's terms, the doctor-patient relationship is "an abstraction embodying the activities of two interacting systems" (1956:586).

The doctor should seek to understand the patient's views and perceptions of the illness and possible treatments, and then determine whether this is an appropriate course to follow, or whether to re-direct the patient towards a more effective treatment regime. Gafni et al (1998) argued that, "as a direct consequence of the asymmetry on

information between the patient and the doctor" (Gafni et al, 1998:347), the doctor should be recognised as acting as an agent for the patient. Consequently, once the patient has reached a decision, they should delegate authority to the doctor, who will take steps to operationalise the decision.

This model allows the doctor to provide information and offers the patient the choice to assess the information provided and reaches their own decision. However, this model can be subjected to criticism. The collaborative model of doctor-patient interaction assumes that social actors know what they want all of the time, and that their decisions remain constant. Despite this Balint and Shelton (1996) considered that such a model reflected a growing trend towards patient autonomy. Doctors are encouraged to educate their patients, who likewise, are encouraged to actively participate in the decision-making process.

Given the vast number of papers published over recent years, it would seem that the shared decision-making (SDM) model has become popular (for example, Charles et al, 1997, 1998, 1999, Edwards et al, 2003). However, it is less certain how realisable SDM might be. The rhetoric of the SDM model sees that although medical knowledge is still valued, patients have become more active in making decisions and ensuring that their opinions are known. Macintyre & Oldman (1977) argued that patients can have 'special' knowledge, of which doctors are mostly unaware - or unable to match, which is built on the patient's own knowledge and experience of their body and their symptom manifestation. Within the encounter, the doctor has medical knowledge and the patient "possesses knowledge of his bodily processes" (Szasz and Hollender, 1956:587) which the doctor does not. However, without the skills of the doctor, it is unlikely that the patient will be able to interpret their symptoms. Therefore, although the patient might be an expert in their own illness experience, they are reliant upon the doctor for the skills to be able to interpret their experience. Thus a partnership between the doctor and the patient is formed.

Charles et al (1998) used the analogy of a tango to demonstrate the extent of the partnership that the doctor and the patient create. They suggested that "it takes two to tango" (1998:681), with each party taking turns to lead the dance. This type of medical interaction allows the doctor and the patient to collaborate, each expressing their own

ideas and sharing their skills. Roter (2000) argued that such a model offers the optimal doctor-patient relationship, as it allows decisions, goals and agendas to be introduced and negotiated by both parties. Information exchange is a two-way process, passing from the doctor to the patient, and from the patient to the doctor.

However, Tuckett et al (1985) claimed that SDM is only possible if both the doctor and the patient can agree upon the problem that they are seeking to resolve. To reach this situation, the patient must verbalise and elaborate upon their problem with the doctor, who in turn must use his biomedical expertise to establish what is happening and then produce an explanatory model. However, such actions still demonstrate that an asymmetry in roles exists. Therefore, given this asymmetry, it appears as if SDM may be a utopian solution rather than a realisable objective.

In addition to the obligations and roles of the doctor and the patient, the competence gap between the doctor and the patient acts to effectively curtail the possibility of sharing ideas on an equal footing (Tuckett et al, 1985). Nevertheless, the asymmetry between the doctor and the patient has been reduced and that which exists, is most likely to be an inevitable product of any service encounter.

Increasingly, the interaction created within the doctor-patient relationship has become a focus of medical sociological inquiry. Early work examining the interactions between the doctor and the patient relied heavily upon each party reporting their version of the events within the consultation (Balint, 1957). For example, during their examination of general practice consultations, Stimson and Webb (1975) discussed how apparent negotiation between the doctor and the patient allowed the patient to express their concerns, including their satisfaction or dissatisfaction with previous consultation outcomes. Such negotiation allowed a less hierarchical relationship to be described. However, the work was criticised due to problems with recalling details accurately in retrospect (Byrne and Long, 1976; Ley, 1988). Consequently, the recent focus upon the doctor-patient relationship and the manner in which the consultation space is used by conversation analysts, who have been able to audio and video record the encounter, has allowed a more in-depth investigation into the actual interaction between the doctor and the patient to occur. The resultant relationship between the doctor and the patient is contingent upon the interaction occurring within the consultation. The consultation

develops due to the joint participation of the doctor and the patient, and the relationship achieved emerges from the negotiations of each party.

The use of conversation analysis (CA) allows the actual processes, as opposed to just the outcomes of interaction between the doctor and the patient to be illustrated. According to Davidoff, "even at its scientific best, medicine is always a social act" (cited in Elywn and Gwyn, 1999:186). Thus, by using CA, one can concentrate on the social processes occurring in the consultation, rather than on 'measurable' outcomes such as patient satisfaction.

As I have shown in this chapter, previous investigations of doctor-patient encounters have illustrated that, "the discourse of physicians and patients is controlled by physicians. [Physicians] ask questions, [and] request that patients respond to specific topics" (Paget cited in Fisher and Todd, 1983:73). However, using a CA stance allows one to see the medical interview as an interactional accomplishment and a social process (Roberts, 2000:153). Rather than being seen as a constant or an inevitability, asymmetry in the doctor-patient relationship is socially produced by both parties through the language used by the doctor and the patient. For example, Maynard argued that asymmetry between doctor and patient is not a product of the "physicians abstract power" (1991:449), but is an interactional achievement. Doctors and patients approach the encounter "in a manner of mutuality and social solidarity" (1991:484). Although 'official' medical accounts are given, the patient's perspective is co-implicated, by for example, the doctor asking the patient, 'what do you think?'. The patient's response is then worked into the medical account given.

The consultation and the ensuing doctor-patient relationship are achievements, produced as a consequence of each party's turns and utterances, which themselves are constructed in order to meet the objectives and obligations of the doctor and the patient role. The consultation is therefore:

> a service encounter, with patients bidding for a service which they quite often seem to have clearly in mind. When in the consulting room, however, they play the game as evidently they feel it should be, deferentially, hiding their definite plans or formatting them as hints, providing the doctor with information from which he can find out what they want him to do.
>
> ten Have, 1995:252.

Such CA insights into the doctor-patient relationship demonstrate that the encounter is strategically constructed and as such, contrast heavily with Parsons' (1951) traditional interpretation of the medical encounter as one with inflexible rules and obligations. Rather than patients adhering to the mastery and superiority of the doctor, as witnessed in a Parsonian model, an interactional stance shows that patients choose to listen to doctors and defer to the greater expertise of the medical profession. In fulfilling their role credentials, patients choose to take advantage of the greater knowledge and expertise of doctors; they are not simply rendered passive by the doctor (Maynard, 1991; ten Have, 1991). Some years after his sick role thesis was published, Parsons subsequently argued that he had been misunderstood. He stated:

> in my earlier work I had stressed the asymmetry of the role patterns of patient on the one side, physician on the other. The quite incorrect implication was made by some of the participants that I had claimed the role of patients to be purely passive, as objects of manipulation, and not as, in any important sense, participative.
>
> Parsons, 1975:257-8.

Nevertheless, as I have implied throughout this chapter, the roles and their associated obligations of both the doctor and the patient, are necessary in order for the doctor to treat the patient, and for the patient to return to health. The gulf between the technically competent doctor and the sick patient who seeks the doctor's skills in order to return to health, will always create some form of asymmetry.

3.3. Conclusion.

I have demonstrated that many opposing models of the doctor-patient relationship have held favour. No model can claim to be superior (Szasz and Hollender, 1956), as each has its place in deciphering a role for the doctor and the patient (Emanuel and Emanuel, 1992). Each model is suitable for certain types of medical encounter and the format can

evolve during the consultation. Consequently, doctor-patient interaction should be seen as creating a dynamic, reciprocal and emergent relationship (Kaplan et al, 1989).

However, regardless of the model practised, a truly egalitarian doctor-patient relationship cannot exist. The interaction between the doctor and the patient demands a set pattern of actions and expectations. The patient requires technical help, the doctor is a technical expert, and via training and expertise, has an institutionalised status qualifying him (sic) to help the sick. Tuckett et al suggested:

> by cultivating an aura of superior expertise, doctors in the past have sought to establish and maintain their economic and social position. As part of the process, lay ideas and expertise have been devalued and the creation and maintenance of a hierarchical relationship between doctor and patient has been established as a norm.
>
> Tuckett et al, 1985:214.

Medicine, as a mechanism of social control, has been a fundamental means of determining the legitimately ill from those feigning illness in an attempt to receive the rewards associated with inhabiting the sick role. However, a number of recent developments have challenged this distinction, and in turn, the doctor-patient relationship.

There has been a change in morbidity patterns. Rather than acute or episodic illnesses, contemporary Western society has seen a rise in the number of people suffering from chronic, debilitating illnesses (Bury, 1997). This changing pattern of morbidity clashes with the patient role expectations offered by Parsons (1951). Patients will not be able to return to full health quickly, and will be required to be freed from their social obligations for longer than a patient who has a short-term illness, thus challenging the social system. These developments could threaten a static model of the doctor-patient relationship. However, given that the doctor-patient relationship continues to exist, despite such developments, Kaplan et al's (1989) description of the doctor-patient relationship as dynamic, reciprocal and emergent is accepted.

The development of genetic medicine has produced a further challenge to the traditional representations of the doctor-patient relationship, and a similar threat to the maintenance of the social structure. Being genetically predisposed to a disease creates a problem for

the doctor-patient relationship in regards to its function as a mechanism of social control. As I discussed in chapters one and two, patients at-risk of a genetic disease are neither currently diseased nor symptomatic, but are asymptomatically ill (Novas and Rose, 2000). The medical gaze has fallen upon "potentially ill, the healthy and the normal" (Armstrong, 1983:9). Consequently, the traditional doctor and patient roles as described by Parsons (1951), are unattainable.

The rise of genetic medicine has therefore altered the boundaries between the doctor and the patient. The uncertainty related to genetic risk, results of genetic testing and the efficacy of prophylactic surgery leave doctors and patients unsure as to what the future may bring. Genetic test results may be inconclusive, and although a positive test will inform a patient that she is at-risk of disease, it will not tell her where or when that disease might develop. Moreover, although patients can have prophylactic surgery to reduce their risk of developing disease, as I discussed in chapter one, surgery is not 100% effective. Subsequently, the doctor cannot ensure that he will meet his obligation to "forward the complete, early and painless recovery of his patients" (Parsons, 1951:450).

In this chapter I have examined many of the different models of the doctor-patient relationship that have been popular in the medical sociology literature, and have discussed the extent to which it is possible for the patient to actively participate in the medical consultation through involvement in treatment decision-making. Although I have argued that patients have been able to play a greater role in the consultation than they once were, I greet the move towards SDM and an egalitarian doctor-patient relationship with caution as it is unclear whether this can be achieved in practice. Whilst the doctor and the patient produce the encounter through their interaction, the relationship cannot be equal. Fundamental status and role differences remain which result in an asymmetrical relationship, making the notion of a 'shared' decision impossible.

Chapter Four. Methods and Methodology.

> There are three major ingredients in social research: the construction of theory, the collection of data and, no less important, the design of the methods for gathering data.
>
> Gilbert, 1995:18.

In the preceding chapters I have reviewed the existing literature that has informed this study. In this chapter, I firstly return to my criticism of the methods used by others, which I first discussed in chapter two, and then move on to discuss the methodology and methods that I applied to examine women's experiences of being at-risk of HBOC.

4.1. Existing studies.

In chapter two, I discussed how many of the existing studies examining women's decision-making and reactions to genetic risk have relied upon measurement of outcomes. I demonstrated my critical stance towards the methods utilised by others whilst examining women's experiences of being at-risk of HBOC. Although the existing research has set out to investigate women's social and psychological responses to HBOC risk, by utilising quantitative strategies, they have removed the woman and consequently the personal experience from the arguments made. By utilising a theoretical framework deriving from social psychology, much of the existing work was fragmented and categorised the women's accounts. I propose that in order to gain a detailed insight into women's experiences, one must use research methods that allow individual experiences to be viewed. In this chapter I discuss my chosen methodology and methods, and develop the argument that "any research situation is a social encounter" (Voysey, 1975:72).

4.2. Methodology.

> The study of method.
>
> Melia, 1997:127.

In this section of the chapter, I examine the methodological stance that I applied whilst carrying out the research. I have relied upon an approach best defined as a conversation

analysis informed ethnography. My approach is neither ethnography in its strictest sense nor a 'pure' conversation analytic study. However, combining these two methodologies allows me to utilise the data collected in the most productive manner whilst examining women's experiences of being at-risk of HBOC.

i. Ethnomethodology and conversation analysis.

Ethnomethodology, developed by the American sociologist Garfinkel in 1967, is the study of the methods that everyday people use to make sense of their lives. Ten Have described how Garfinkel was, "interested in the procedural study of common-sense activities" (1999:6). Language is the medium in which to investigate this and illustrates how, "social action is accomplished through the participants' use of tacit, practical reasoning skills and competencies" (Wooffitt, 1995:288).

Conversation analysis (CA), developed by Sacks and Schegloff, grew out of ethnomethodology. Greatbatch et al suggested that CA "represent[s] a general approach to the study of social interaction" (1995:32). CA "is not concerned with language per se, but rather it recognises that talk is a primary vehicle for the accomplishment of social actions in human society" (Heath and Luff, 1995:312). CA is concerned with the "competencies which underlie ordinary social interaction" (Heritage, 1984:241; original emphasis), and examines how people make sense of their social lives, by focusing on the minutiae of the structure of the actual language used. It is not just what people are saying or doing, but where the utterance sits within the "interactional and sequential features of talk" (Heath and Luff, 1995:309) and how it is said, that is of concern.

CA allows one to focus upon what is happening in the interaction by contextualising all occurrences to what has gone before, and to what follows. Ford et al stated, "a conversation between two individuals is not the sum of two monologues. It is reciprocal and each statement has a relationship with the preceding and subsequent statements" (2000:557). A CA stance allows one to view utterances as being shaped by their context, but also as renewing that context (Heritage, 1984). Thus, language accomplishes social action. Language is key in accomplishing shared meanings and interactions, because it "orders our perceptions and makes things happen…language can

be used to construct and create social interaction and diverse social worlds" (Potter and Wetherall, 1987:1).

ii. Ethnography.

In outlining ethnography, Hammersley and Atkinson described a method, or set of methods which, "in its most characteristic form involves the ethnographer participating, overtly or covertly, in people's daily lives…….watching what happens, listening to what is said, asking questions – in fact, collecting whatever data are available to throw light on the issues that are the focus of the research" (2000:1). They continued, describing how, "the primary aim [of ethnography] should be to describe what happens in the setting, how the people involved see their actions and those of others, and the contexts in which the action takes place" (Hammersley and Atkinson, 2000:6).

To carry out an ethnographic study, a variety of qualitative methods, including observation and interviewing are normally used. Dingwall claimed that an ethnography can "include all research based upon naturalistic modes of inquiry within a predominantly inductivist theoretical framework" (1980a:871). Thus, whilst examining the experience of being both a <u>woman</u> at-risk of HBOC, and a <u>patient</u> at-risk of HBOC, the ethnographic methods of participant observation and in-depth interviewing were used during data collection.

iii. Combining ethnomethodology, ethnography and CA.

Traditionally, researchers arriving from an ethnomethodological or CA stance have rejected the use of ethnographic data, arguing that it is "expert information gathered from natives' interview responses or as recollection of unrecorded social events, [and] theoretical information about contexts" (Nelson, 1994:307). However, a re-examination of ethnographic data enables it to be seen as "transcription-extrinsic information about intentions…necessary to identify actions and thus carry out conversation analytic studies of any type" (Nelson, 1994:307-8). Recently Maynard has added to this debate, arguing that although in its purest sense, CA "eschews ethnographic description" (2003:65), the meanings given to an utterance depend upon the context or the

'sequential organisation' to use CA terminology, in which it was made. Thus, to examine how social actors make sense of their lives, one must have some understanding of their social life, and ethnography provides this.

Moerman suggested, "that CA has a preoccupation with the 'dry bones' of talk and is 'bloodless' and 'impersonal' with regard to 'richly experienced human reality'" (cited in Maynard, 2003:69). However, if combined with ethnographic methods, CA can both examine "the events, actions, norms, values…from the perspective of those being studied" (Murphy et al, 1998:74) as well as the actual interaction occurring.

Focusing in detail upon women's experiences of being at-risk of HBOC, I focused upon the utterances made during the consultation observations and the interviews. Throughout this thesis, I argue that data should be seen as accounts rather than literal descriptions of events or feelings. Such accounts are influenced by both the cultural context of the experience being recalled and demonstrate 'the interaction order' (Goffman, 1967) in the form of talk-in-interaction.

Dingwall argued that "any encounter involves the parties demonstrating their own, and checking each other's, ability to 'see' the world in a particular way, the cultural competence which embraces interactional competence" (1980b:153). Consequently, if utterances are recognised to be demonstrative, "interview responses cannot be treated as a guide to actual behaviour" (Murphy et al, 1998:105). Rather, data should be regarded as an account, a rehearsed, or edited version of what occurred. The objective of such accounts is to make the "system meaningful to the outsider" (Gould et al, 1974:xxiv). Thus, like Mills (1940), I consider that, "the reasons men [sic] give for their actions are not themselves without reason" (1940:904). Man's (sic) talk can be seen as a form of talk-in-action; the accounts given enable researchers to focus upon <u>what</u> image is constructed by the talk, and <u>why</u> it is important that this image is sought.

Mills suggested that the "social function" of accounts is to enable moral work to be produced (1940:904). Murphy (1999) extended this argument, claiming that accounts permit people to construct, "an <u>image</u> of themselves as moral members of society" (Murphy, 1999:191; emphasis added). People construct their talk to demonstrate that their actions meet socially accepted behavioural and social norms, or should they not,

that there was a plausible, and acceptable reason for any ensuing deviant behaviour. However, such are the pressures to conform to social norms, that accounts, justifications and rationales for actions will be prepared; people will have pre-arranged justifications for their actions and rationales for their decisions. Murphy referred to "well rehearsed accounts" (1999:192) whilst discussing the accounts that mothers gave regarding their decision to bottle feed their children, rather than follow social expectations and breast feed. In agreement with Baruch who found, "stories have been treated as situated accounts constructed to display their competencies as an interview respondent….and demonstrate their adequate parenthood" (1981:277), Murphy concluded that the accounts given by the women were constructed so that they would be recognised by the interviewer as 'good mothers'.

Therefore, as this discussion of the use of moral accounting has demonstrated, "understanding language is not, in the first instance, a matter of understanding sentences, but of understanding actions – utterances – which are constructively interpreted in relation to their context" (Heritage, 1984:139). However, moral accounting can be problematic. Comparing their own observations of doctor-patient interaction and the accounts subsequently produced by patients, Webb and Stimson recalled, "in the accounts that people gave of their consultations the patient is portrayed as having taken a very active part in the encounter, and the patient's opinions, judgements and subjective feelings figure prominently. Our own observations, by contrast, reveal the patients as less directive and less active than the doctor" (1976:108). Therefore, acknowledging the construction of moral accounts allows the researcher to move beyond the actual utterances, and focus upon what the utterances are doing. Dingwall considered that social actions are produced:

> in the expectation that you will understand them in a particular way. Your understanding reflects your expectations of what would be a proper action for me in these circumstances.
>
> Dingwall, 1997:56.

As a result, extending Dingwall's suggestion, it would seem that, "it is not necessary to spell out what [a participant] is doing for him to be engaged in a particular activity" (Baruch, 1981: 278). Taking the epistemological position that recognises the usefulness of talk-in-action enables the researcher to see beyond the story being told, and instead

focus upon why the participant needs to construct the account that portrays them in a certain manner. Like Murphy (2000), this research therefore does not question the facticity of the stories that women told whilst being interviewed, after all, "interview data cannot offer us literal descriptions of the respondent's reality" (Dingwall, 1997:60). Rather, the women's talk "engages reflexively with the social and normative context in which it occurs" (Murphy, 2000:318), produces an interpretation of the event which is being spoken about (Hawkins, 1984), and enables the interviewee to carry out some form of impression management (Goffman, 1959; Dingwall, 1997).

In the following data chapters, I illustrate how the women were directing their "talk…. [to] demonstrat[e] that they have acted responsibly by subjecting the advice offered to critical appraisal and that their actions are the prudent outcomes of such deliberations" (Murphy, 2003:457). Thus, like Silverman, "we need not hear interview responses simply as true or false reports on reality. Instead, we can treat such responses as displays of perspectives and moral forms" (1993:107). Consequently, social interactions, such as the interview, are an opportunity for impression management (Goffman, 1959) in which interviewees are "required to demonstrate their competence in the role in which the interview casts them" (Dingwall, 1997:58).

4.3. Methods.

> [The] research procedures actually employed.
>
> Melia, 1997:127.

In the following section of the chapter, I discuss the methods that I employed whilst carrying out the research which informs the subsequent data chapters.

> Research cannot be programmed…. its practice is replete with the unexpected.
>
> Hammersley and Atkinson, 2000:23.

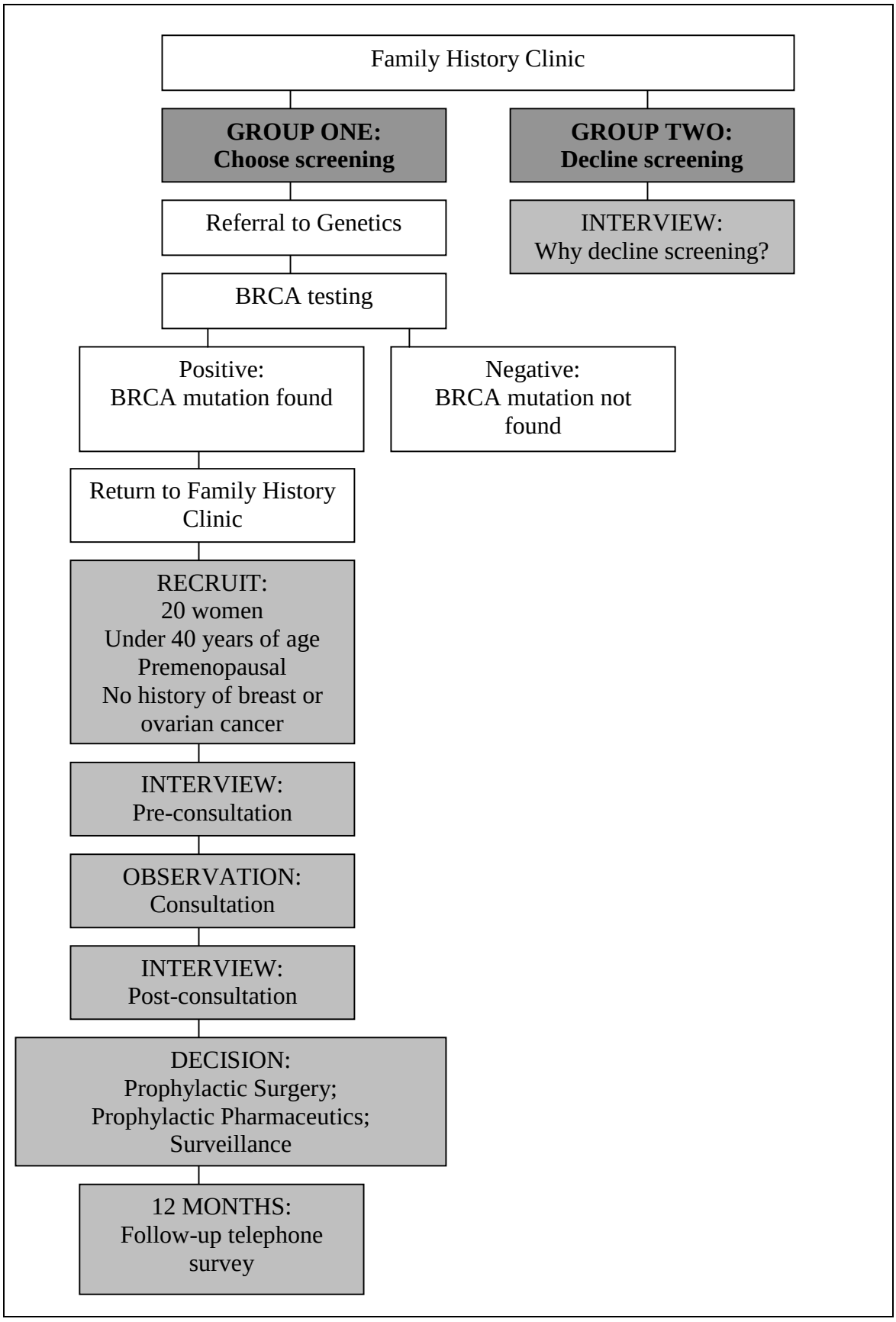
This research was carried out in co-operation with Hospital X, a regional centre that specialised in breast cancer genetics in the Midlands. The hospital was "one of the country's leading centres for breast screening, diagnosis, treatment, research, professional education and training….[seeing] more than 35,000 patients with breast problems each year" (Hospital X, 2002). The specific clinic where the research was

based had approximately 21,000 referrals per annum.
Hammersley and Atkinson's quotation (above) demonstrates that upon its conclusion, much of the social research that is performed will have altered from its original conception. This research follows such a pattern.

Adjustments to the intended research design occurred for a variety of reasons, but were mostly shaped by the difficulties experienced firstly in gaining access to the study site, delays in achieving ethical approval and changes in the characteristics of the patients referred to the Family History Clinic. Before addressing the research design that was followed, I will briefly describe how the plans altered during the course of the study.

I had initially intended that the research would investigate women's experiences of being at-risk of HBOC by incorporating the perspectives of 20 pre-symptomatic, pre-menopausal women below the age of 40 years, who were defined as being at-risk following their referral to the Family History Clinic. I would also interview a small group of women about why they had decided how to seek screening or testing. The following chart illustrates such a design.

Figure eight: Original research design.



As figure eight demonstrates, the original research design would involve the participation of two groups of women presenting at the Family History Clinic at Hospital X. The first group, shown on the left-hand side of the chart, would consist of women who had decided to have genetic testing. I would interview the women inhabiting this group prior to their consultation, and seek to establish what they wanted from the consultation that would follow. The consultation would be observed, and the women interviewed again after the consultation. In these second interviews, women would be asked about their perceptions of the encounter and any decisions that they had made. Lastly, I would perform a telephone survey 12 months later, with the aim of following-up upon the women's accounts that they had delivered in the second interviews. The second group, shown in the right-hand side of the chart, had declined the opportunity to discover if they carried a BRCA mutation. The second group would be interviewed about their decision not to have genetic testing, and about what factors had influenced this choice.

Following the clinical team's approval of the research design, an application to undertake the research was submitted to the Local Research Ethics Committee (LREC) at Hospital X.

Gaining approval for this research design from the (LREC) at Hospital X was dependent upon four points being addressed:

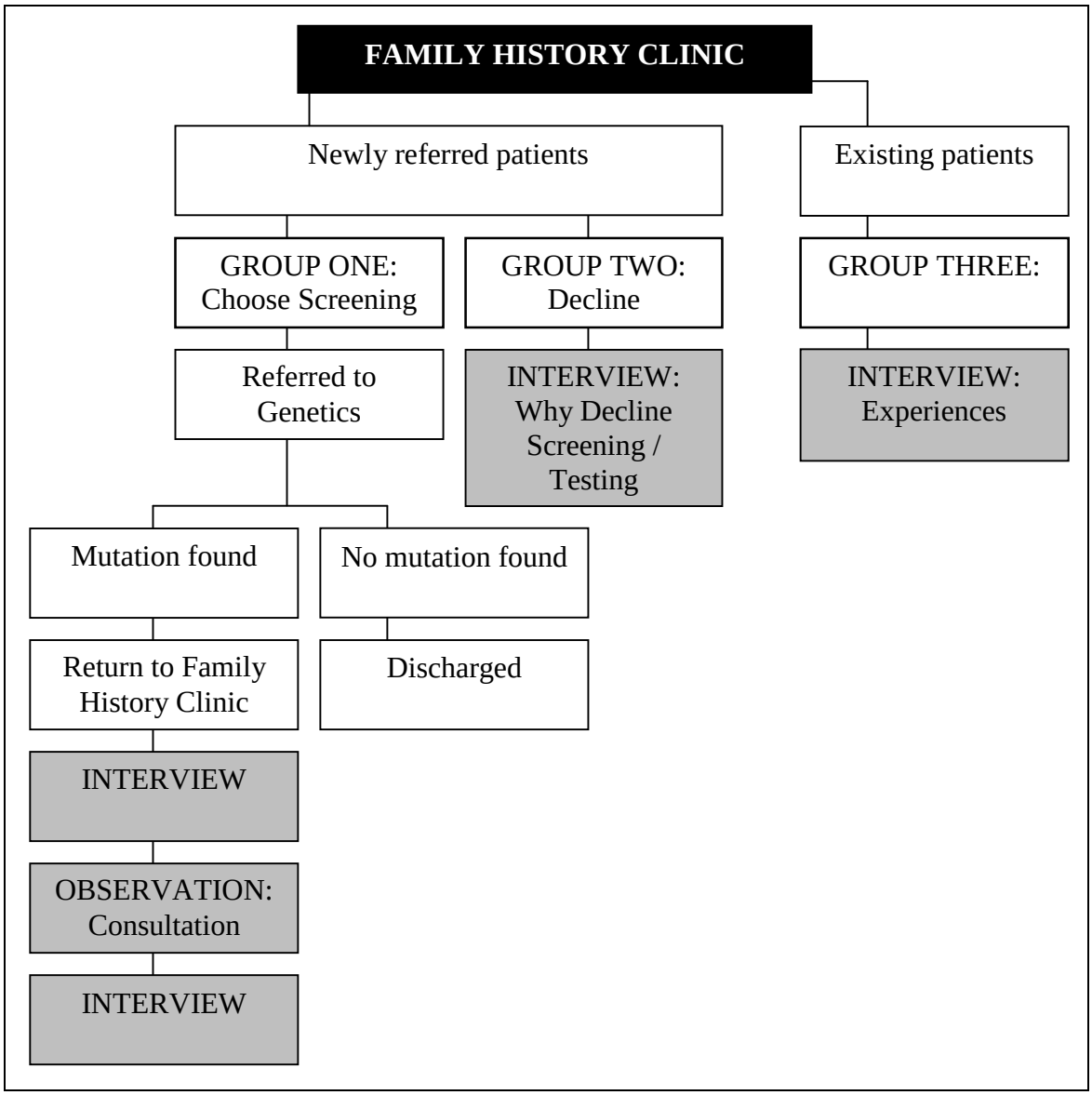
1. The initial contact letter to the patients being recruited should come from somebody known to them at Hospital X, rather than from myself, who would at the time of the letter, be unknown to the patient.
2. Provision should be made for emotional and clinical support should participants become genuinely upset during the interview.
3. Clarification of the University's data storage policy.
4. Alterations to the research information sheet that participants would receive, in terms of the inclusion of extra material and the rewording of existing text.

The four points raised by LREC were easily and quickly addressed by myself and the senior breast cancer care nurse at the Family History Clinic, who would write the invitation letter and provide the respondents with the emotional and clinical support

outlined in point two. The changes requested by LREC necessitated the approval of the senior members of the clinical team. However, this process was problematic and created an unforeseen delay[10]. Consequently, some seven months passed before the amended documents were returned to LREC and approval to commence the research was granted. During this period, it became clear that the Family History Clinic was experiencing a decline in the number of women who would be eligible for recruitment into group one of my sample. The clinical team therefore suggested that I should not limit the number of women recruited to group two, but should invite all women who declined to undergo testing to participate in the interviews. Moreover, the clinical team also proposed that I interview some of their 'old' patients: women at-risk of HBOC, whose consultations I had not observed at the clinic. These women would form group three (see figure nine below), and would be interviewed about their HBOC experiences in retrospect. Additionally, plans to carry out a telephone follow-up survey were abandoned so to ensure successful completion of the research within the available time frame.

[10] This lengthy delay was unavoidable due to personal problems experienced by one of the clinical team.

Figure nine: Second amendment to research design.



This change in research design necessitated a reapplication to LREC, which resulted in a further small delay before data collection could commence. Once approval had been granted by LREC, a number of pilot observations were carried out at the clinic.

The aim of these observations was to allow me to:

1) Assess where I could best position myself within the consultation in the least obtrusive manner.
2) Acquaint myself to the information delivery by the staff during the consultation.

3) Discover if it would be possible to collect effective data without taking notes during the consultation, but after the patient had departed.

Hammersley and Atkinson argued, "when studying the setting, the ethnographer is also a novice. Wherever possible, he or she must put him-or herself into the position of being an 'acceptable incompetent'" (2000:99). Although when coining this term, Hammersley and Atkinson had described how an ethnographer could gather the best quality data if they were alien to the surroundings, I use the term in a slightly different manner. Given that I was not participating in the medical interaction, it was important that I did not influence or affect the nature of the consultation. I was 'incompetent' because I was new to the environment, and whilst this did enable me to be more aware of the situation (as per Hammersley and Atkinson), it also meant that I had to learn how not to interfere with the flow of the interaction between the doctor and the patient. For example, I had to learn where to sit so that I was out of the eyesight of both the doctor and the patient, and how to appear as if my presence in the room was not uncommon. Emerson et al (1995) recommended that to avoid problems, the researcher should locate themselves on the margins of the interaction. In following Emerson et al's suggestion, I found that although the layout of each consulting room varied, it was always possible to find a space out of direct eyesight of both the doctor and the patient.

Secondly, I had to become familiar with the medical content of the information that the doctor was likely to impart during the consultation. I had to ensure that should the patient look at me, I would not give the impression that I was shocked or distressed by what the doctor had said. The pilot observations therefore gave me an opportunity to learn how to be a impartial figure within a highly emotive and sensitive environment. Furthermore, having been present when the doctor performed a breast examination on one patient, and casually been passed their bra to hold whilst the examination was performed, I subsequently decided that it was inappropriate for me to observe this part of the consultation, as it did not relate to any of my research questions. Adler and Adler commented, "private locales ought to remain protected from the prying eyes of sociologists" (1998:101). I discussed my presence with the breast care nurse (hereafter known as Nurse H), and we decided that it was inappropriate for me to observe women's breast examinations. To reduce the disruption that my leaving the consulting room would create, it was decided that both Nurse H and myself would leave the room

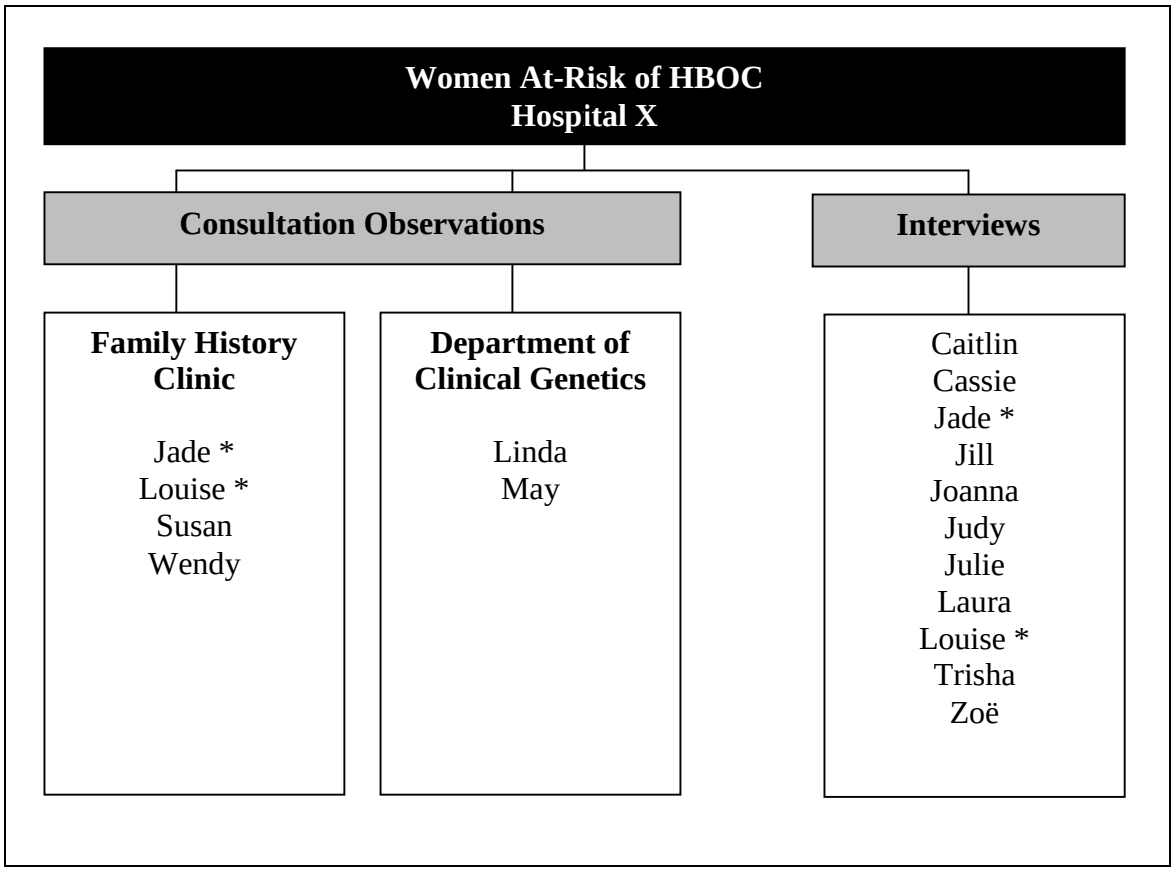
whilst the doctor carried out the examination, and the doctor would then call both of us back in once he had completed it.

Lastly, on a practical note, I found that relying upon my memory to write fieldnotes after the consultation enabled me only to collect descriptive data. Such fieldnotes could not capture the type of detailed ethnographic notes that would allow me to focus upon the interaction occurring between the doctor and the patient. I reached the decision that in subsequent consultations I would make notes whilst in the room.

A further outcome of undertaking the pilot observations was finding that the original LREC approved sampling criteria for group one, of 20 pre-symptomatic, pre-menopausal women below the age of 40 years was too restrictive. None of the women that I had observed during the seven pilot observations had met such a strict criteria. Consequently, I proposed to change my sampling criteria to include all women 'at-risk'. This change to the sampling criteria required a further resubmission to the LREC panel, and approval was granted in December 2002.

Given the difficulties that I have discussed in this chapter in regards to gaining access, ethical approval and amending the research design, Hammersley and Atkinson's suggestion that "research is a practical activity requiring the exercise of judgement in context; it is not a matter of simply following methodological rules" (2000:23) is apt. Much like Lincoln and Guba (1985) advised, the moral of this chapter is that research design is emergent.

Figure ten: The Final Sample[11].



i. Recruiting participants and the role of the gatekeeper.

Development of HBOC is characterised by its early onset, and in chapter one, I summarised the various definitions of 'early onset' that have been provided. Compared to cancer developing sporadically, HBOC is rare; it affects only a limited number of women each year (Cooper, 2000). For example, between 1998 and 1999, just 1,173 BRCA1 and BRCA2 genetic tests were undertaken in the UK, and not all of these would have reported on a positive mutation. This limited population is compounded when focusing upon just one geographic region, and therefore reduced the limited number of women who met the sampling criteria furtherstill.

[11] Asterisks by names indicate that the women were interviewed as well as having their consultation observed. The data deriving from the Department of Clinical Genetics was provided by Dr Pilnick, from recordings stored in her data archive, and is discussed in depth in chapter five.

In chapter one (page 31) I outlined the extensive clinical criteria used to assess risk status. At Hospital X, a woman was considered to be at high-risk of developing HBOC if she had one 1st or 2nd degree relative with breast and ovarian cancer below the age of 50, two 1st or 2nd degree relatives with breast or ovarian cancer below the age of 50, and four close relatives who had had breast or ovarian cancer. My sampling criteria corresponded with the screening eligibility characteristics set by the Family History Clinic at Hospital X. Moreover, as I discussed earlier in the chapter, the alterations to my research design resulted in the removal of any age exclusion from the sampling criteria.

Given the limited population, I decided to use an opportunistic sampling method. Opportunistic sampling "follows no strict, logical plan" (Honigmann, 1982:81). The strategy offered the most flexible approach available, which would allow me to include whatever cases were made available to me. Thus, as Murphy et al suggested, "in some cases, particularly where the phenomenon is highly sensitive, or illicit, the population of interest is highly mobile, or the group of interest is known to be reluctant to participate in research, opportunistic sampling may be the only avenue open to the researcher" (1998:92).

The selection of the sample was very much dependent upon the access that the clinical team allowed me to their patients and case notes. I came to depend upon Nurse H to invite me to the consultations and to agree (or disagree) to my interviewing her patients.

At Hospital X, Wednesday morning clinics were routinely used to see family history patients. However, the number of consultations carried out depended on both the number of symptomatic patients to be seen and the doctor's surgical lists. As such, it was not certain that each clinic would yield any suitable patients to participate in my research. Consequently, it was decided that I would contact Nurse H on a weekly basis and she would inform me of whether there would be any suitable consultations for me to observe that week. She therefore came to be the central gatekeeper driving my access to the clinical site and data collection.

In addition to her role as my gatekeeper to the clinical setting, Nurse H was instrumental in the construction of the sample of women in group three. She granted me

access to her case notes, and files that included details of all the women that she had seen at the Family History Clinic who had been offered genetic testing. My sample was therefore constructed via an examination of the files and case notes. I made a record of patients whose cases appeared as if they would be able to present a varied representation of the experience of being at-risk of HBOC. Cases were selected according to the patient's year of birth, number of children, marital status, test result, previous diagnosis of cancer and management option chosen. The composition of group three is illustrated in figure 11.

Figure 11: Composition of sample group three[12].

Patient	**Test Result**	**Management Option [12]**	**Cancer Diagnosis**	**Year of Birth**	**Marital Status**	**No. of Children**	**Recruited**
1	BRCA2	BPM	No	1971	Divorced; Living with Partner	2 (pregnant with 3rd)	Yes
2	Untested	N/A	No	1951	Married	3	Yes
3	BRCA1	PH / BPO	No	1964	Married	3	Yes
4	BRCA1	Bilateral Mastectomy / BPO	Yes: Breast Cancer	1944	Unknown	Unknown	No
5	BRCA2	PH / BPO	No	1960	Married	1	Yes
6	BRCA1	BPM / BPO	No	1957	Married	1	Yes
7	BRCA2	Bilateral Mastectomy / BPO	Yes: Breast Cancer	Unknown	Married	2	No
8	BRCA1	BPM / BPO	Yes: Breast Cancer	1964	Married	Unknown	No

[12] The shorthand should be read as follows; BPM: Bilateral Prophylactic Mastectomy, BPO: Bilateral Prophylactic Oophorectomy, PH: Prophylactic Hysterectomy.

Patient	Test Result	Management Option [12]	Cancer Diagnosis	Year of Birth	Marital Status	No. of Children	Recruited
9	BRCA2	Bilateral Mastectomy / BPO	Yes: Breast Cancer	Unknown	Unknown	Unknown	No
10	BRCA2	Bilateral Mastectomy / Surveillance	Yes: Breast Cancer	1966	Unknown	Unknown	No
11	BRCA1	Bilateral Mastectomy / Surveillance	Yes: Breast Cancer	1973	Married	1	Yes
12	BRCA1	Bilateral Mastectomy / Surveillance	Yes: Breast Cancer	1973	Separated	0	No
13	BRCA1	BPM	No	1956	Married	1	No
14	BRCA1	Bilateral Mastectomy	Yes: Breast Cancer	1970	Remarried	1	No
15	BRCA1	Surveillance	No	1976	Divorced	2	Yes
16	BRCA1	Bilateral Mastectomy	Yes: Breast Cancer	1965	Married	3	Yes
17	BRCA1	Awaiting BPM / BPO	No	1963	Married	2	Yes
18	BRCA2	Surveillance	No	1974	Single	0	Yes
19	Negative	N/A	No	1971	Married	1	Yes

I discussed each of the 19 cases depicted in figure 11 with Nurse H. I was informed that it would be inappropriate for me to contact four of them (patients 4, 8, 9, 14). Two of these women had moved out of the area (patients 9,14). Nurse H asked if I would exclude the remaining two women, reasoning that she did not think it was suitable for me to see them as they were not coping with their risk well, or would not welcome the attention of a researcher (patients 4, 8). Cicourel advised that "if formal [access] channels are used… the possibility exists that the researcher's study will be restricted or that he might be refused the opportunity to study at all" (1964:54-5). Similarly,

Hammersley and Atkinson warned that, "gatekeepers may…attempt to exercise some degree of surveillance and control, either by blocking off certain lines of inquiry, or by shepherding the fieldworker in one direction or another" (2000:66). Whilst my sample for group three was guided and shaped by Nurse H, I continue to believe that this was a condition of the access that I had negotiated.

I wrote to the 15 women that Nurse H agreed to my contacting, asking if they would agree to participate in the research and followed the letters up a week later with a telephone call. 11 of the women agreed to participate, and I subsequently arranged a time and date for the interviews[13]. The interviews were scheduled at a time and place convenient for the women, with the aim of disrupting their lives as little as possible by them agreeing to participate in the research. Once arrangements had been agreed, I sent the women a confirmation letter and an outline of the research[14].

The consultations that were observed were self-selected by Nurse H, in the manner described previously. I was invited to attend five consultations at the Family History Clinic, and the patients were asked whether they would agree to my presence in the consulting room. Only one woman refused to allow me to observe her consultation. The data concerning the two remaining observation patients was collected by Dr Pilnick in the course of a different research project carried out at Hospital X, and was kindly made available to me.

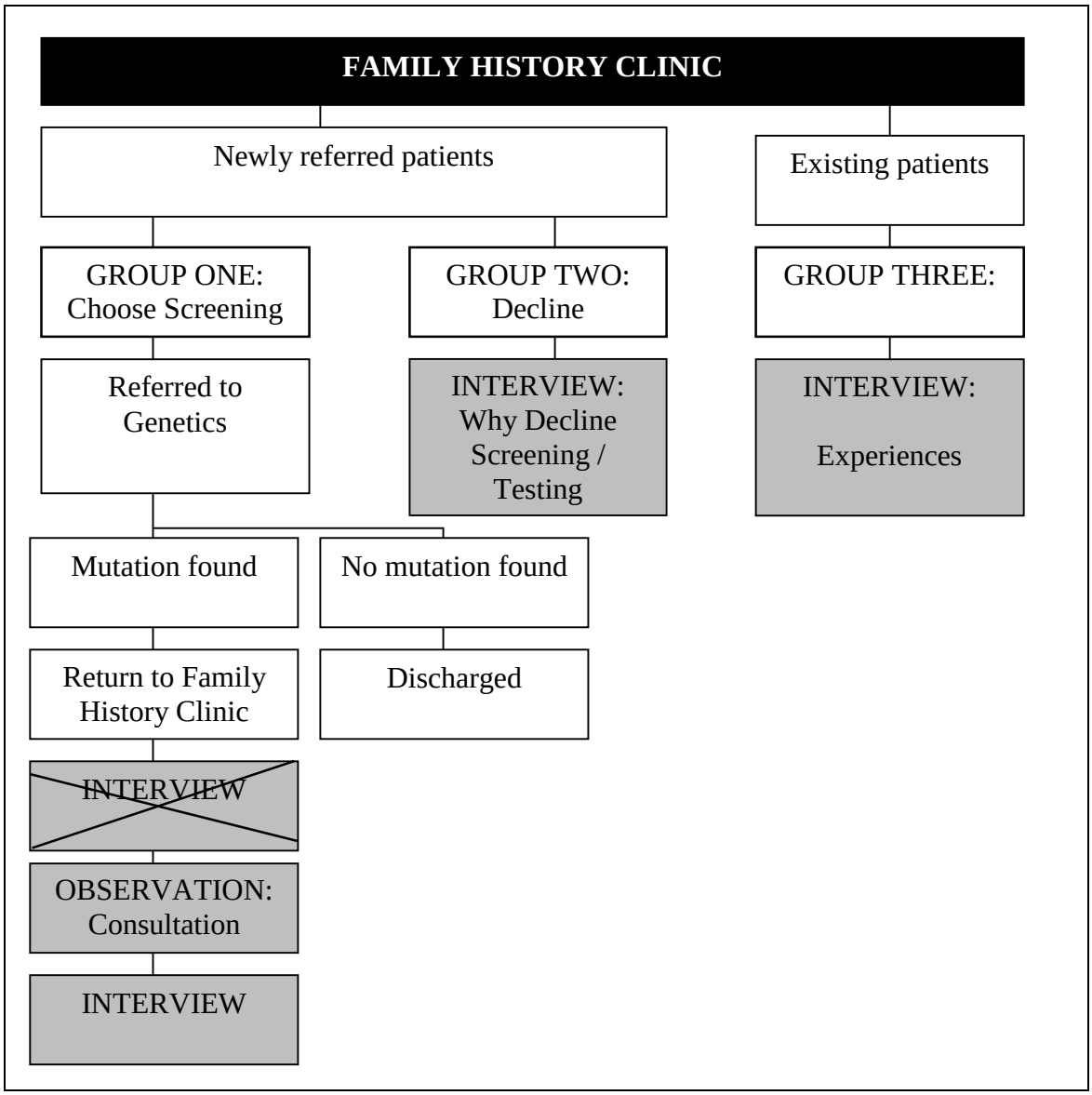
[13] Patients 7, 10 and 12 could not be contacted; patient 13 decided not to participate in the research.
[14] A copy of the patient information sheet can be found in the Appendix three.

Figure 12: Composition of Observation Sample.

Patient	Test Result	Management Option	Cancer Diagnosis	Year of Birth	Marital Status	No. of Children	Interviewed?
1	BRCA2	Surveillance	No	1974	Single	0	Yes
2	Negative	N/A	No	1971	Married	1	Yes
3	Unknown	Unknown	No	1971	Married	2	No
4	Unknown	Unknown	Yes: Breast Cancer	1957	Unknown	2	No
5	Unknown	Unknown	No	1945	Married	2	No
6	Unknown	Unknown	No	1968	Married	4	No
7	Unknown	Unknown	Unknown	1958	Married	1	No

The final research design differed slightly from that presented in figure nine (page 95). However, the final sample was comprised women recruited from all three groups. The only difference between the research design illustrated in figure nine, and that followed was that pre-consultation interviews were not performed. The women were not contacted prior to their appointment at the Family History Clinic to inform them about the research, and so no opportunity for pre-consultation interviews was made available.

Figure 13: The final research design.



In total, as demonstrated in figure ten (page 98), 16 women participated in the research, in both the interviews and consultation observations (a response rate of 73%). Two women refused to participate and four could not be contacted[15].

[15] The final sample was therefore comprised of six women who were observed in their consultations, and 12 women who were interviewed. However, two of the women were observed and interviewed and so have been counted only once. The 16th woman was not initially recruited, but was the sister of one of the original 15 women invited to participate. She was visiting her sister at the same time as the interview was scheduled, and decided to participate and share her experience of being at-risk of HBOC.

ii. Sample Characteristics

Ten women had a maternal family history of breast and ovarian cancer. A further three had a paternal family history. However, the line of possible inheritance is unknown in the three remaining cases. Eleven women consented to undergo genetic testing, one declined and it is unknown whether four opted for testing because of the restrictions imposed to ensure that access and ethical approval was granted, which meant that I was unable to follow up their cases.

A varied age-range has been included within the sample. At the time of the research, the women's ages ranged from 27 years old to late 50s, although the majority of the women observed and interviewed were in their 30s. Of those women choosing to undergo genetic testing, four were in their 20s, five were in their 30s and two were in their 40s. Of those tested, six women were BRCA1 positive, three women were found to be BRCA2 positive and two women were not found to carry either mutation. Five women chose to undergo prophylactic surgery and their age at time of surgery ranged from 28 to 45 years old. Three women faced surgery because they had a malignant tumour. Their ages ranged from 26 years old to late 30s. 12 of the women were married or living as married, one woman was in a relationship but did not live with her partner, another was divorced and two women did not mention their marital status. Only one woman was childless.

Having recruited my sample, I undertook two phases of research.

iii. Phase one: observation.

> Often when we think of the social scientist as observer, we conjure up an image of a laboratory scientist in a white coat, jotting notes on a clipboard while observing people from behind a one-way mirror.
>
> Adler and Adler, 1998:81.

The majority of the observational data discussed in this thesis were collected during four consultations observed at the Family History Clinic over a period of five weeks[16].

[16] I was unable to carry out any further observations, despite contacting Nurse H and asking if it would be

Doctor E carried out three of these consultations, whilst Doctor F performed the remaining encounter.

A difficulty with observational research is that the investigator may inevitably affect the interaction despite their best intentions. Whilst I undertook a minimal role in the consultation, it remains unknown whether I had any effect upon the consultation.

My attendance at the consultations was arranged according to the clinical team's commitments and the patient's agreement. Hammersley and Atkinson suggested that the research participant should be "informed about the research in a comprehensive and accurate way" prior to giving their consent (2000:264). However, as I discuss here, the issue of consent from the patients whose consultations I observed is problematic. The British Sociological Association's Ethical Guidelines outline:

> as far as possible participation in sociological research should be based on the freely given informed consent of those studied. This implies a responsibility on the sociologist to explain in appropriate detail, and in terms meaningful to participants, what the research is about, who is undertaking and financing it, why it is being undertaken, and how it is to be disseminated and used.
>
> BSA, 2002; emphasis added.

Once in the clinic however, it was Doctors E and F and Nurse H who sought consent by informing the patients that 'a student from the university wanted to observe their consultation as part of their doctoral research', rather than myself as the researcher, as the BSA guidelines suggest. The patients were told that I would not participate in the consultation, but would observe the encounter. The clinical staff then elicited the patient's verbal consent to allow me to observe the consultation.

The manner in which patients' agreement was sought for the observational phase of the study draws attention to the difficulty in determining a standardised level of informed consent. Gribble argued, "in many instances, informed consent amounts to nothing more than a signature on a piece of paper" (1999:175). However, given the manner in which the clinical team sought consent from the patients regarding my attendance in

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possible for me to attend the clinic. It was explained that one of the breast care nurses had left, and Nurse H's workload had doubled. As a consequence, she was under pressure to prioritise symptomatic patients ahead of women at-risk.

their consultation, no written consent was given. Rather, patients verbalised their consent.

Given the ethical issues that I have outlined, should I have insisted upon gaining the patients' written consent? In hindsight, no harm was caused by my presence in the consulting room, and I did not carry out any covert observation. All of the patients knew who I was and why I was there. If the doctors had thought that my presence was unsuitable, or the patient did not wish for me to observe, then I did not enter the consultation room. Moreover, the manner in which consent was sought allowed me to stay in the background and not affect the flow of the consultation. Whilst 'in the field' I was constrained by the finite amount of time scheduled for each consultation; as the research was not 'invasive', I reached the conclusion that I had to trust the clinical team's judgement regarding the suitability of my presence in the room.

Consultation data was collected with the use of detailed field notes, in which the verbal dialogue spoken by the doctor and the patient was documented verbatim. Whilst I had initially aimed to audio-record the consultations, I decided against this after my pilot work. My aim was to remain in the background of the consultation and minimise the influence that either myself or the research would have upon the interaction occurring between the doctor and the patient. The presence of an audio-recorder may have threatened this. Both the doctor and the patient may have been conscious of the recorder and altered their behaviour accordingly. Comparably, it is usual for third parties such as medical students, to be observing consultations and thus my presence may not have been perceived as unusual.

Hammersley and Atkinson considered that "fieldnotes are the traditional means in ethnography for recording observational data" and consist of "relatively concrete descriptions of social processes and their contexts" (2000:175). Offering further instruction, Emerson et al suggested that when making fieldnotes, it is best to "recount what happened in fine detail" (1995:14), whilst "the goal is to get as much down on paper in as much detail and as quickly as possible, holding off any evaluation and editing until later" (1995:47). The fieldnotes I made were also swayed by my chosen methodological strategy of a CA informed ethnography, and I therefore focused upon the talk-in-interaction that occurred. Consequently, the notes I made focused upon the

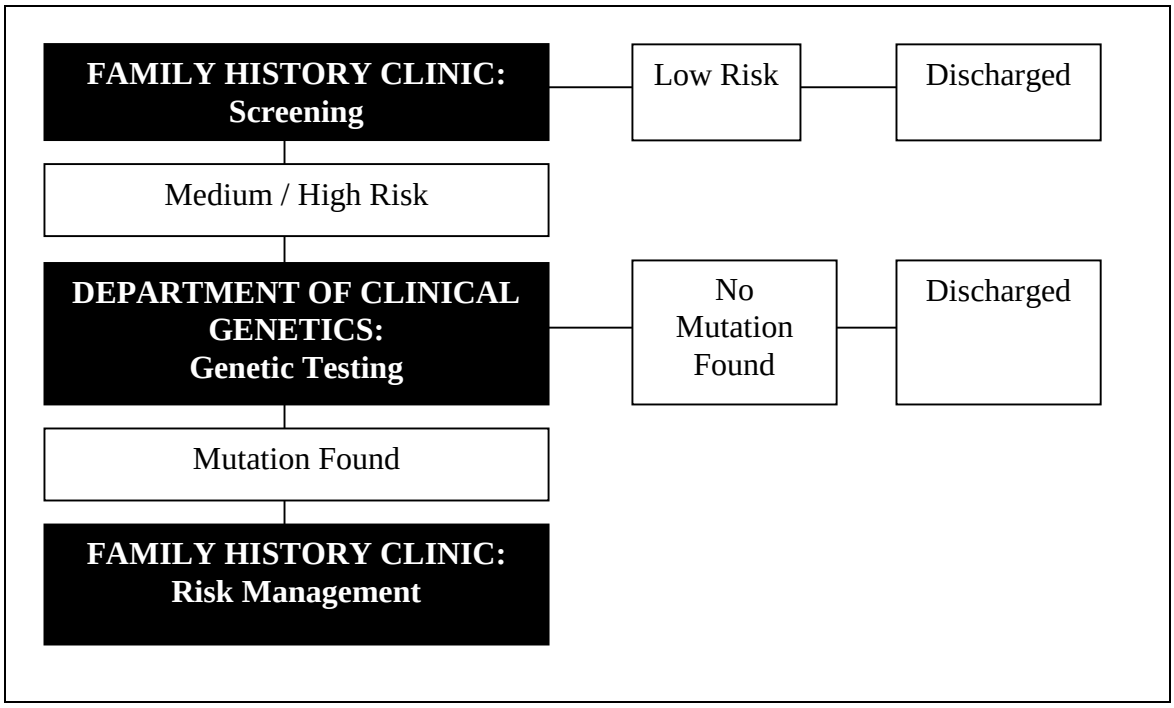
utterances that the doctor and the patient made. Thus, although the observational data was not audio-recorded and was therefore unable to be transcribed using CA notation, it has been possible to illustrate some level of the interaction that occurred between the doctor and the patient.

My fifth piece of observational data came from the data archive of Dr Pilnick, who kindly supplied me with a recording of a genetic counselling consultation involving two women at-risk of HBOC (observation patients 5 and 6 in figure 12, page 103). The consultation was one of 15 recorded over a three-month period at the Department of Clinical Genetics at Hospital X[17]. The 15 consultations were distinct cases and involved a wide variety of genetic conditions, including HBOC, Turners Syndrome, Huntington's disease and Fragile X Syndrome.

The inclusion of this consultation is not at odds with the data already discussed. As figure 14 illustrates, the women whom I observed at the Family History Clinic, and those I interviewed would also have been referred to the Department of Clinical Genetics.

[17] See Pilnick (2002a) for an in-depth explanation of the methods used to gather the data.

Figure 14: The consultation process at Hospital X.



The recording of the Department of Clinical Genetics consultation was transcribed using standard CA notation[18] and analysed using a line-by-line detailed approach, focusing on the interaction between all parties in the consultation. I discuss my mode of analysis in greater detail later in the chapter.

iv. Phase two: interviews.

Collins (1998) referred to interviews as conversations with a purpose. However, the interview is not a conversation, as the interviewer "defines what the parties are going to talk about" (Dingwall, 1997:58). The interview "is a deliberately created opportunity to talk about something which the interviewer is interested in and which may or may not be of interest to the respondent" (Dingwall, 1997:59). Thus, the interview is not an example of naturally occurring speech, but is a staged opportunity characterised by "asymmetrical information-gathering….in the sense that one party questions, while the other answers" (Mazeland and ten Have, 1998:16). Lee discussed the inherent power relations within the interview situation, and drew upon Oakley, who argued:

[18] Examples of such notation can be found in Appendix five.

> the person who is interviewed has a passive role in adapting to the definition of the situation offered by the person doing the interviewing. The person doing the interviewing must actively and continually construct the 'respondent' (a telling name) as passive.
>
> Oakley, cited in Lee, 1993:108.

Therefore, whilst Collins suggested, "the goal of finding out about people through interviewing is best achieved when the relationship of interviewer and interviewee is non-hierarchical" (1998:6), this is considered to be unattainable. Ultimately the researcher holds a more powerful position than the researched, as they are the party asking the questions and driving the focus of the research. However, the respondent is not as passive as Oakley described. The respondent has the power to alter or influence the interview, by changing the subject, refusing to talk, or even terminating the interview.

To minimise any hierarchical effect between researcher and researched, I chose to use an open-ended questioning strategy. Silverman argued, "most interactionists tend to reject pre-scheduled standardised interviews and prefer open-ended interviews" (1993:95). Open-ended questions allow the respondent to define their own experiences, have a flexible questioning structure, and enable the respondent to raise issues that interviewer has not previously considered. Voysey extended this rationale, commenting "this method allows the interviewer to…. capitalise on 'leads' offered by the respondent" (1975:67). Whilst flexible, this interview strategy is not unstructured. Murphy et al argued "the term 'unstructured' is misleading insofar it is impossible to conceive of an interview which is totally without structure" (1998:112). Whilst allowing "respondents to display their ways of understanding the world" (Murphy et al, 1998:113), the use of a topic guide strategically directs the focus of the interview towards the issues that the researcher wishes to cover.

Breast cancer, once a taboo topic (Weisman, 2000:217), remains a sensitive and emotional issue[19]. Thus, in the interviews, asking women to talk about their experience of the disease, or being at-risk of the disease, required caution, care and sensitivity. My

[19] During analysis of the interview data, I became aware that women were using humour as a coping strategy whilst discussing their experience of being at-risk of HBOC. Existing studies have focused on humour as a tool to resist professional dominance (Griffiths, 1998) and as a coping strategy for sex-workers (Sanders, 2004).

chosen interview strategy was selected with this in mind. Johnson and Clarke argued that "defining 'sensitive' research is problematic", but "any research topic, depending on its context, is potentially sensitive" (2003:421). They suggested that typical examples of 'sensitive' research draw upon emotional issues, and involve HIV/AIDS, mental health, cancer, terminal illness and death and dying.

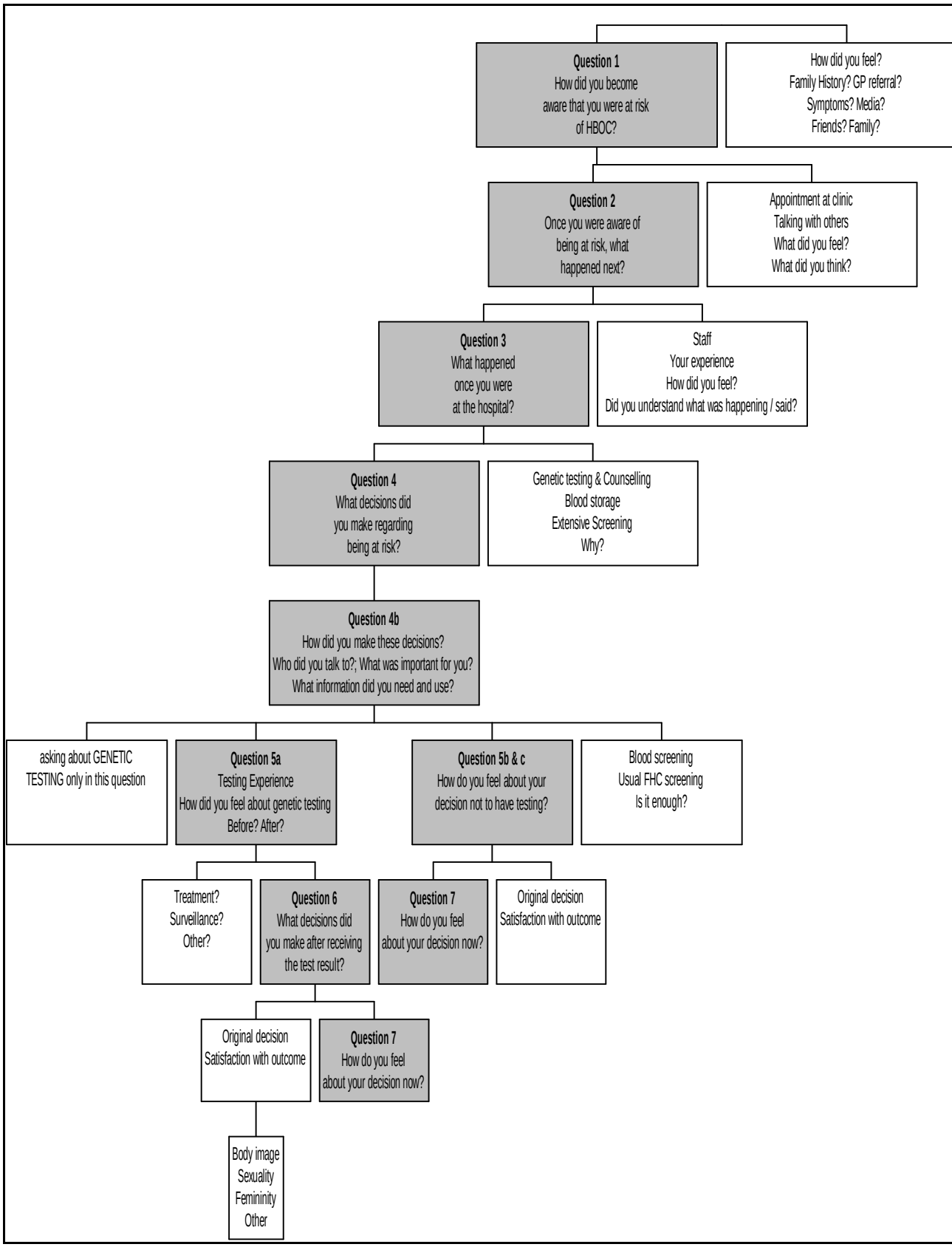
To prepare for the interviews, I had designed an interview guide (figure nine, page 97) that would address many of the issues related to my research question. Questions to be included in the interview guide were influenced by themes investigated in the existing body of knowledge regarding women's experiences of HBOC, talking to Nurse H and observing family history clinic consultations. While interviewing women about their breast loss and breast reconstruction, Kasper found that "the interview guide proved to be more of a hindrance than an aid, imposing the researcher's areas of interest and interrupting the flow of a woman's recall" (1995:203). Therefore, given the warning that Kasper had offered, the interview guide was designed so that the ensuing interviews would be fluid, informal and flexible. In practice however, I relied upon two main questions.

My opening question asked the women to "tell me about yourself and how you came to the Family History Clinic". This question prompted lengthy responses. Mazeland and ten Have referred to such questions as multi-turn exposés, which "delineate one or more topics of interest to the research and instructs the informant to treat these at length" (1998:2). They argued that such interviews could be characterised by "a loose kind of control by the interviewer on the informant's talking. During his [talk] the latter is largely self-directing, choosing his own relevancies, categories and level of detail" (1998:4). The responses to my multi-turn exposé were information rich and provided the opportunity to ask follow-up questions. My second question had three parts, and I used it to conclude the interview. The closing questions were: 1) "how do you see your future?", 2) "have your issues with being 'at-risk' been resolved?", and 3) "what would you change if you could?".

I used my interview guide to remind myself of the types of questions that I might want answered. I was also able to keep field notes of the interview, both within a notebook and on the interview schedule, and then refer back to my notes should I wish the

interviewee to elaborate upon an earlier made point. However, the majority of women spoke about the topics themselves without me prompting them to do so. In a minority of cases a more structured interviewing approach was needed, and the topic guide was followed. The interview guide used is shown in figure 15. The grey shaded boxes distinguish my seven ‘structured’, pre-defined questions, from the prompts (clear boxes) that were used as an aide memoir.

Figure 15: Interview guide.



With the interviewees' permission, all of the interviews were audio-recorded, using a digital voice-recorder and flat microphone. Unlike the traditional tape-recorder, digital voice recorders are not so constrained by the length of recording time. For example, the data card that I used to record the interviews could store up to ten hours of data. Whilst the interviews were never envisaged to last this long, the length of the available recording time meant that I did not have to worry about needing to replace tapes after 30 minutes or how this would affect the interaction. Moreover, the equipment is much smaller than other recording paraphernalia, and was less physically obtrusive than might otherwise have been.

In all cases, the interviews were carried out in participants' homes, and arranged at times suitable for the interviewees. The informal nature of the questioning structure employed was mirrored by the setting in which the interviews were performed. Most interviews were carried out in participant's living rooms, where both the interviewee and I sat on the sofa, or around the kitchen table, drinking cups of tea and coffee. However, as I have already discussed, these interviews were not naturally occurring conversations between two women, as I had asked that the women talk to me, and had determined what the topic of 'conversation' would be. Nevertheless, the setting allowed the talk occurring to be as near to a conversation as an interview situation would allow. Women were encouraged to talk 'freely' about their HBOC experience, and some thanked me for providing them with such a cathartic opportunity in which they could talk without fear of upsetting someone close to them or someone involved in their treatment.

In total, 11 in-depth semi-structured interviews were performed. In one interview, the participant's sister (who had also experienced being at-risk of HBOC) was present and asked if she could also contribute. The interviews ranged in length; the shortest was 30 minutes, whilst the longest interview lasted approximately one and a half hours. However, once the audio recording had ceased, the majority of the women continued to talk about their experiences of being at-risk of HBOC, and I recorded this in my field notebook once I had left the participant's home. Warren et al argued that the space occurring after the recording had stopped should be termed "after the interview", and involved "a strip of time between the end of the formal interview and the culmination of leaving rituals" (2003:93). They claimed that talk occurring "after the interview" was

more likely to be informal and in contrast to that in the interview itself. However, I found there was little difference, and women continued to talk in the same manner and about the same subjects which they had done in the interview.

Eight of the interviews were transcribed verbatim; the remaining three were selectively transcribed. I justified the change in transcription technique as I felt that data saturation had been reached. Moreover, the three selectively transcribed interviews were the last to be carried out, and took place a few months after the others. By this time, initial data analysis had been carried out; these interviews were used to check the authenticity of the original eight, and to test whether my initial analytical categories were sufficiently developed.

4.4. Analysis.

> Data analysis is described as 'a range of techniques for sorting, organizing and indexing qualitative data'.
>
> Mason, cited in Mauthner and Doucet, 2003:415.

My chosen methodological perspective determined that all data should be understood as a product of a social encounter, regardless of whether that encounter was an interview or an observation. Moreover, my inductive analytical stance rejected any pre-formed themes or categories. Bryman and Burgess described how, "data are collected and after a general reflection on 'issues of concern' categories which fit the data are generated (1994:4). Arguing similarly, ten Have suggested, "analytic induction is a technique used primarily by qualitative researchers to access commonalities across a number of cases and thereby clarify empirical categories and the concepts that are exemplified by the cases included in a category" (1999:39). Consequently, data analysis was driven and "developed from phenomena which are in various ways evidenced in the data of interaction" (Heritage, 1984:243).

Analytic induction was originally linked to the search for 'universals'; "today, however, analytic induction is often used to refer to any systematic examination of similarities (Ragin, 1994:93). Thus, the data were analysed in a manner similar to that described as 'constant comparison' by Glaser and Strauss (1967). Constant comparison allows for

inductive and continual refinement of the analytical themes. Dey suggested that categories help to organise and conceptualise the data, and are "therefore a crucial element in the process of analysis" (1993:112). The use of categories as adopted here, enables the analyst to consider and reconsider "what is really meaningful in the data" (Patton, 1990:406). Whilst awareness of possible themes arose from those found in the existing literature, the categories that emerged were formed as inductively as possible, solely from focusing upon what is in the data.

i. Observational Data

To analyse the observational data, I started with a line-by-line, and then case-by-case analysis of the consultations. In each consultation, I focused upon how each party was making sense of the interaction, and paid attention to what was happening, thus drawing on an ethnographic stance, and how it was happening, using a more interactional, CA influenced strategy.

Whilst I did not follow the conventions of CA transcription to their fullest extent, for example, by notating every rise in intonation, each breath, or a change in the speed of the language, the approach utilised did allow the interaction occurring between each party to be illustrated. Therefore, although not a 'pure' CA interpretation of the data, the resulting transcription does demonstrate the moment-to-moment organisation of the talk (Pilnick, 2002a), and illustrates how the talk is both context shaped and context renewing (Heritage, 1984). It has therefore been informed by CA theory.

The analysis was "unmotivated" (Roberts, 2000); analytical themes were allowed to emerge from the data. Subsequently, the themes emerging from each consultation were compared with those from other consultations. The inductive formation of categories was continually refined and resulted in the following themes: 1) informed decision-making, 2) active patients, 3) directiveness or non-directiveness, 4) information transfer, 5) pronoun shifts, and 6) questions and responses.

The analysis of the genetic counselling consultation supplied by Dr Pilnick followed a similar manner to that utilised whilst examining the other consultation data. Whilst utilising a case-by-case comparative method of constant comparison, my analysis of the

consultation data was also informed by a conversation analytic stance. Such a stance allowed a line-by-line, turn-by-turn micro level investigation of the interaction occurring between the doctor and the patient, in which the minutiae of each utterance were focused upon. Emerging themes demonstrated the interactional negotiation and creation of each party' identification. The analysis of the observational data was subsequently developed in order to examine the difficulty in identifying the patient (chapter five), and to supplement women's accounts of the type of doctor-patient relationship they had experienced (chapter six).

ii. Interview Data

Like the observational data, following transcription the interviews were analysed using an inductive approach. Again, themes that addressed the research questions were allowed to emerge. Each transcription was focused upon individually, and was repeatedly re-read and coded until the data had been exhausted. This stage was determined when no additional themes emerged. The preliminary analytical themes emerging from the interview data were: 1) relationship with doctors, 2) notions of heredity and responsibility, 3) the future, 4) body-image, and, 5) process of diagnosis.

Following completion of the initial analysis, I returned to the analytical themes and found that upon re-examination, they could be extended and developed in order to shape the story that is subsequently told in the data chapters. Thus, the final analytical themes were: the patient, the doctor, genetic testing decisions and surgical decisions and implications. Each of these themes forms a separate data chapter. During the final data analysis, it became apparent that the data collected demonstrated that the experiences of women at-risk of HBOC may not be that different from those of women who actually experienced breast cancer. Accordingly, my research question was adjusted to demonstrate this finding.

The chosen analytical framework views the stories told by the women during the interviews as accounts. The analysis of the interview data was therefore shaped by the recognition that accounts are constructed by participants to direct the manner in which they and their actions are interpreted by others. In relation to this thesis then, it is suggested that women's accounts regarding whether to undergo genetic testing and

subsequently have risk-reducing surgery have a moral significance. Murphy (1999) argued that when reaching a decision, an individual either knowingly conforms to, or break social norms. Consequently, when constructing their rationales, the women were actively producing explanations that would enable their behaviour to be excused or justified by others.

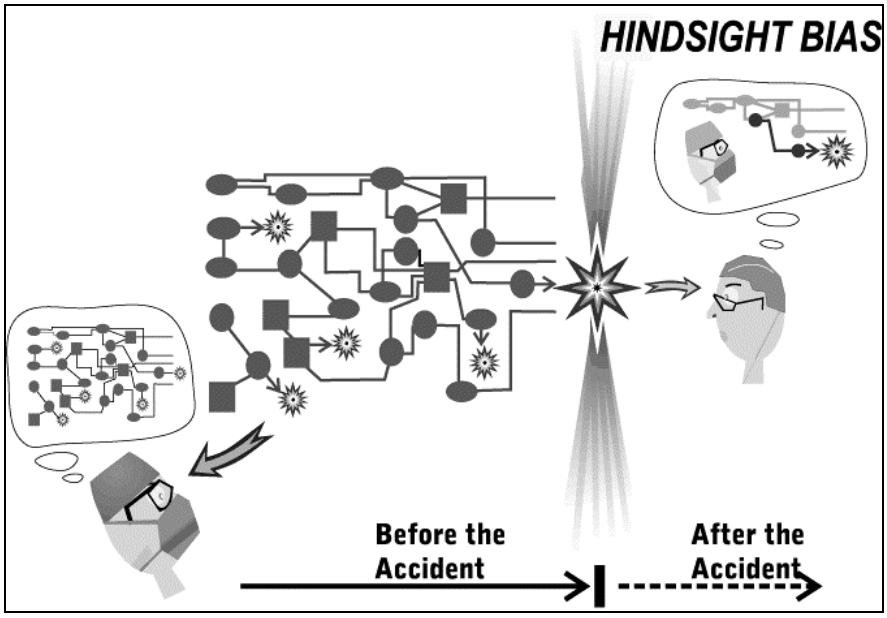
Wilkinson commented that, "talk is designed by speakers for its specific contexts, and is doing something relevant to, and occasioned by that context" (2000:444). It is conjectured that the accounts given by the women I interviewed were constructed their narratives so that they could be perceived as moral members of society. Murphy argued that in producing such accounts, respondents were "engaged in constructing images of themselves, for themselves, and for the interviewer, as normal, moral, [and] responsible" (2000:303).

However, it is also possible the accounts received during the interviews were influenced by the retrospective nature of the research. It is a limitation of the data that the accounts were collected some time after the events which they describe. I am unable to ascertain how the accounts might have differed had I been able to interview women whilst they were deciding whether to undergo genetic testing and risk-reducing surgery. Similarly, it is unknown how the delay between the event and the interview shaped the resulting accounts.

The time interval between the actual event being recalled and the interview taking place may have led to problems with recall. Moreover, perceptions of events or the saliency of particular concerns may have altered with time. Earlier I referred to a similar problem discussed by Webb and Stimson (1976), who pointed to the differences between the accounts they received from patients regarding their level of activity within the consultation, to that which they observed themselves. It is therefore likely that the accounts that I received were affected by hindsight bias.

Referring to the effect of hindsight bias on subsequent explanation, Cook et al described how, "knowledge of outcome biases our later judgments about the processes that led up to that outcome" (1998:11). Continuing their explanation of hindsight bias, they offered the following visual example.

Figure 16: Hindsight bias.



Source: Cook et al, 1998:12.

Calland et al proposed a similar explanation to that offered in figure 16, and suggested that "retrospective analysis….leads to a conclusion" (2002:1008). It is therefore likely that in the time between making their decision about genetic testing and risk-reducing surgery, and being interviewed, the women would have reflected upon the influences that swayed their actions. Consequently, what in hindsight appeared to be an important influence upon their decision-making may not have been so influential at the time the decision was made.

Several of the women I interviewed had undergone genetic testing and risk-reducing surgery four years before they spoke to me. Therefore, they had had four years to be influenced by hindsight bias, and 'make sense' of their experience of being at-risk of HBOC. Consequently, the retrospective accounts that I received are a presentation of an event, not a literal depiction of the women's actual behaviour. Heritage and Atkinson highlighted a similar problem when taking interview data at face value, arguing that data is not an "acceptable surrogate for the observation of actual behaviour" (1989:2). They explained that when relying upon a participant's report of events, it is vital that researchers are aware of the well-established gap between beliefs and actions, and between what people say they do and what they actually do. As a result of the

retrospective data, it is likely that there is a discrepancy between women's accounts of their experience of being at-risk of HBOC and what this actually was.

Having discussed the methodology and methods used whilst carrying out this research, I now turn to the collected. In the following chapters, I address the question, **"are women's experiences of being at-risk of HBOC genetically exceptional?"**. Before this, I contextualise the data chapters with an introduction to the genetic exceptionalism debate.

SECTION II. The Data Chapters.

Introduction to the data chapters

5. Who is the patient?
6. The doctor-patient relationship.
7. The genetic testing decision.
8. The surgical decision.

Introduction to Data Chapters.

> No branch of science has created more acute or more subtle and interesting ethical dilemmas than genetics.
>
> Burley and Harris, cited in Lewens, 2004:326.

The following four chapters discuss and analyse data that were collected from observations of consultations between doctors and women at-risk and interviews with women at-risk of HBOC. Where pertinent, additional data published by other authors supplements the arguments made.

The chapters individually address the experiences of women at-risk of HBOC, and concentrate upon: the difficulty in establishing who is the patient within the consultation, when the inherited nature of the disease implicates more than one individual (chapter five), the doctor-patient relationship (chapter six), the decision to undergo genetic testing to search for a possible mutated gene (chapter seven) and lastly, the decision to have risk-reducing surgery (chapter eight). Collectively, the four data chapters examine the experiences of women at-risk of HBOC. They follow a common theme, asking whether there is anything exceptional or unique about the illness and decision-making experience of women at-risk of an inherited genetic disease compared to that of patients who fall under the medical gaze because they are unwell.

Genetic Exceptionalism.

Friedman Ross stated that the term 'exceptionalism' was:

> introduced into health care in 1991 when Bayer described 'HIV exceptionalism' as the policy of treating the human immunodeficiency virus (HIV) differently from other infectious diseases, particularly sexually transmitted diseases.
>
> Friedman Ross, 2001:141.

Following the advances made possible by the mapping of the human genome, individuals have been offered the opportunity to discover if they carry a genetic

mutation, which would signify that they were at increased risk of developing a particular disease. Two forms of genetic test currently exist: diagnostic and predictive (Pilnick, 2002b). Diagnostic genetic tests, like non-genetic diagnostic tests, are used to determine the nature of a current medical problem. Predictive genetic tests investigate whether a person may develop a disease in the future. Two types of predictive test exist: testing may uncover autosomal dominant disorders, which signal the inevitable onset of disease, such as Tay Sachs or Huntington's disease, or autosomal recessive disorders, in which a person has a predisposition towards developing a disease, such as HBOC (Pilnick, 2002b).

The term 'exceptionalism' has been linked with genetics in order to illustrate the differences between genetic and non-genetic diseases. Advocates of genetic exceptionalism consider that "genetic information is sufficiently different from other health-care information" (Friedman Ross, 2001:141) Consequently, it follows that if genetic information is different from non-genetic information, then the subsequent illness experience would also be "sufficiently different". In supporting the notion of genetic exceptionalism, Annas et al explained:

> to the extent that we accord special status to our genes and what they reveal, genetic information is uniquely powerful and uniquely personal, and thus merits unique private protection.
>
> Annas et al, 1995:365.

Murray (1997) attributed three factors to support the notion that genetic information is different from routine health information. He suggested that genetic tests are exceptional because 1) they are prophetic and can act as a future diary, 2) can be stigmatising and victimising, and, 3) have the potential to divulge information about individuals other than the person undergoing the test. The support for genetic exceptionalism is extended with Green and Botkin's argument that differences exist between genetic and non-genetic tests because genetic testing uses "molecular information to draw conclusions about a person's past, present and future health" (2003:572).

Those who champion the notion of genetic exceptionalism consider that because of its prophetic nature, the information uncovered by testing is vastly different to routine (non-genetic) medical information. However, for others "the arguments for 'genetic exceptionalism' - for treating genetic information and tests as somehow special – are not compelling. Outside the high penetrance, single gene disorders, genetic tests, like most other medical tests, provide evidence only of statistical risks" (Meltzer and Zimmern, 2002:863).

Similarities between genetic and routine medical testing, both their purpose and the manner in which they are carried out, suggest that genetic tests are not exceptional. Green and Botkin (2003) described how the aim of both genetic and non-genetic tests is to identify those at-risk of a disease, and how the procedure for obtaining the DNA sample and carrying out the test is similar to other, routine, diagnostic tests.

Friedman Ross (2001) acknowledged that whilst genetic information has a prophetic quality, it is likely that environmental and non-genetic variables such as lifestyle, diet and exercise are more significant risk factors when explaining the cause of disease. She stated that although genetic testing may implicate family members, so too do other medical tests. For example, sexually transmitted infections and diseases, such as chlamydia, syphilis and HIV/AIDs, can be passed onto third parties, and have the potential to inform those parties about the likelihood of an individual carrying the infection. A similar situation exists with the diagnosis of Alzheimer's disease, a neurological condition in which sufferers experience the premature onset of senility. Because of the symptoms of the disease, members of the patient's wider family become implicated, because of the patient's need for constant care. Moreover, although most commonly occurring sporadically, Alzheimer's disease can be hereditary (Public Health Genetics Unit, 2003).

Murray (1997) suggested that genetic testing might stigmatise and lead to discrimination. However, Friedman Ross pointed to many social differences based on race, religion, class, culture, language and gender that occur indiscriminately. She thus concluded that:

genetic information is not qualitatively different from other medical information.

Friedman Ross, 2001:145.

Having briefly outlined the main arguments for and against genetic exceptionalism, I now move on to discuss whether the experience of women at-risk of HBOC, and the decisions that they made, might be considered as exceptional or uniquely associated with being at-risk of a genetic disease. In each of the following four data chapters, I address the research question, **"are women's experiences of being at-risk of HBOC genetically exceptional?"**. In order to support or reject the research question, and thus the genetic exceptionalism thesis, the discussion within each chapter asks whether there is anything unique about women's experiences that are instigated because of the genetic nature of their risk.

The Hypothesis.

In order to establish whether the genetic exceptionalism thesis has integrity, I therefore propose test a hypothesis much in the same manner as the celebrated falsification theory of the white and black swans.

Dingwall and Murray (1983) employed a similar tactic when examining the difficulty of locating children into Jeffrey's hypothesis that patients could be "broadly [categorised] into good and bad patients" (1979:104). The key determinant to being labelled 'good' or 'rubbish', was that the "patient must not be responsible, either for their illness or for getting better" (Jeffrey, 1979:99). However, other rules emphasised that the patient should not attend the Accident and Emergency Department (A&E) with 'trivial' cases that did not restrict their normal activities, should not perceive their condition to be desirable and lastly, may refuse to co-operate with the medical team.

Dingwall and Murray tested Jeffrey's hypothesis by examining the effect that the introduction of child patients into A&E has upon the good/rubbish classification. By using Jeffrey's categorisation of good or bad patients, Dingwall and Murray found that "children seem consistently to break the rules which …..are invoked by staff to produce the category of 'bad' patients" (Dingwall and Murray, 1983:132). As discussed above, central to the application of the label of 'bad' patient is that the person is perceived to be

responsible for their condition. However, as Dingwall and Murray highlight, "the vast majority of children are responsible for their own injuries, in the sense that the injuries are caused by some act committed or omitted by the child" (1983:133).

Moreover, unlike trivial adult cases, most childhood injuries do not result in a visit to A&E, and those that do may not restrict the child's level of activity. Dingwall and Murray referred to children attending the A&E department with severe limb fractures who still managed to play in the activity area of the waiting room. Lastly, Dingwall and Murray explain how children are "notoriously uncooperative" (1983:133), and refuse to be examined or receive painful medical treatment. Consequently, Dingwall and Murray rejected Jeffrey's hypothesis that all patients could be "broadly [categorised] into good or bad patients" (Jeffrey, 1979:104), as "children fit the commonsense criteria of 'bad' patients induced by Jeffrey at least as well as drunks, overdoses, tramps or trivia" (1983:134). Moreover, whilst drunks, overdoses, tramps and trivia "receive variously punitive treatment – delay, inattention, verbal hostility, vigorous restraint" (Dingwall and Murray, 1983:134), children attending A&E did not. Jeffery's hypothesis that only two typifications of the patient exist had therefore been falsified, as Dingwall and Murray "identified at least three classes of patients: 'good' patients,…..'bad' patients,….and 'children'" (1983:134).

In order to test the validity of the genetic exceptionalism thesis, and respond my research question, "are women's experiences of being at-risk of HBOC genetically exceptional?", I will test the hypothesis that: **genetic medicine and the knowledge that it produces, is somehow special, unique or different from routine, non-genetic, everyday medical encounters and the knowledge resulting from such consultations**.

The hypothesis, and thus the genetic exceptionalism thesis will be upheld or refuted against the proposition that the experience of being at-risk of a genetic disease recounted by the women is "qualitatively different" from any other health-related experience (Friedman-Ross, 2001:145).

If the hypothesis is upheld, it follows that women's experiences of being at-risk of HBOC are dissimilar from those experienced by patients who have been diagnosed with

a non-genetic disease. If the hypothesis is refuted, it follows that there is nothing exceptional about women's experiences of being at-risk of HBOC.

I begin the hypothesis testing by addressing whether the inclusion of more than one patient in the consultation might be considered as genetically exceptional.

Chapter Five. Who is the Patient?

> Genetic information, by definition, does not apply uniquely to individuals. Knowledge of one person's genetic status allows us to draw inferences about those to whom he or she is related.
>
> Kent, 2003:17.

In this chapter I examine the problematic notion of whom the patient might be identified as within the genetics consultation. Annas et al commented that genetic information is "uniquely personal" (1995:365). However, I demonstrate that when discussing genes and genetic inheritance, more than one individual is involved. By focusing upon the genetic consultation and the identity of the patient, I consider whether the difficulty of identifying a sole patient is exceptional to genetics consultations.

5.1. Patient or patients?

Popular definitions of the term 'patient' describe "a person receiving or registered to receive medical treatment" (Tulloch, 1995:1114), or "one who is suffering from a disease or a disorder and is under treatment for it" (Felscher, 1999:263). However, such definitions are not all encompassing; they do not account for the experiences of those women who participated in this research. These women were neither suffering from a disease, nor receiving any medical treatment for the condition at the time of referral to the Family History Clinic and Department of Clinical Genetics. It is quite possible that such an explanation describes a large percentage of patients investigating their genetic risk.

At the genetics clinic, the aim of the session is to "construct a pedigree, confirm the diagnosis in affected individuals, estimate the risk of a mutation for predisposition to the condition, and, in some cases, request molecular testing" (Donnai and Elles, 2001:1049). Consequently, the majority of people presenting at genetic consultations are at-risk of developing a disease. Novas and Rose referred to "the asymptomatically ill" (2000:469). Secondly, the above definitions of 'patient' do not mesh with the experience of those participating in the genetic consultation. It is likely that more than one person will be implicated by the threat posed by the genetic risk. By its very nature,

genetics investigates cells that are inherited from one's parents. Thus, the focus of the investigation is not upon just one unwell individual. Parker and Lucassen (2004) likened the involvement of third parties in the medical consultation to the difference between joint and individually held bank accounts. They commented:

> genetic information is shared by more than one person, much like the information about a joint bank account.
>
> Parker and Lucassen, 2004:166.

Finkler et al described how "genetic prognostications apply to the aggregate rather than the individual" (2003:404). Hence, a woman found to have a positive BRCA mutation would have inherited this from at least one of her parents. Moreover, it is possible that other members of her family may be at-risk of carrying the mutation. Thus, Finkler et al considered that "with the medicalisation of family and kinship, the individual is no longer the sole patient" (2003:409). Subsequently, as Kenen et al argued,

> the practice of medicine will increasingly be medicine of the family rather than the traditional physician/patient dyad, especially where a genetic condition is involved.
>
> Kenen et al, 2003b:838.

In these circumstances, just who should be considered to be the patient: the person presenting for the consultation, or members of their direct or extended family? This difficulty in defining 'the patient' creates a further challenge. Should the individual or members of their wider family reach the decision to seek, and undergo genetic testing?

Using a single genetic counselling consultation, I discuss the difficulty of establishing the identity of the patient in light of the assertion that genetic medicine deals with families rather than individuals. In responding to the question, "who is the patient?", I examine a theme that has received relatively little interest in published research (for example, Cox and McKellin, 1999; Hagoel et al, 2000; Parker and Lucassen, 2004). This is surprising as it is an issue that fundamentally challenges the traditional format of the doctor-patient relationship and medical encounters.

Traditionally, the medical encounter has been studied as if only two parties, the doctor and the patient, have been involved (for example, Parsons, 1951, Szasz and Hollender, 1956). Others such as Strong (1979) have argued that family members and other clinical staff also participate in the interaction. However, the development of genetic medicine has heralded a shift away from the traditional focus of the doctor-patient relationship, as outlined by Szasz and Hollender (1956) amongst others. Increasingly, the gaze of medical enquiry now focuses not upon the patient, but upon the gene. Genetic conditions, disorders and pre-dispositions are inherited from germ-line mutations passed from parent to foetus at the time of conception, and can be inherited through generations. Consequently, Pilnick argued:

> by their very nature…genetic disorders can and do implicate not just a single individual, but also that individual's family.
>
> Pilnick, 2002b:80.

Pilnick's argument is reinforced by Armstrong et al (1998) and Hallowell (1999), who similarly specified that genetics focuses upon biological relatives. As such, genetic medicine has extended the view that illness is not localised to one patient, but rather implicates other family members.

In any genetics consultation, participants have to decide who is to be recognised as 'the patient'. The patient may be the individual referred to the consultant, or members of their family, either immediate or extended. Whilst sociological insights about the family have emphasised that the term 'family' is a social category, in the genetic consultation, the family is defined biologically.

Failure to distinguish whom the patient is can lead to difficulties, such as that reported by Pilnick (2002a), where each person presenting at the consultation had their own agenda. Further problems can arise within the genetic consultation; for example, it is not uncommon for people to present at genetic clinics for testing and report that other members of their family have declined the opportunity to 'reveal their true identity' (Armstrong et al, 1998). This can create ethical dilemmas for the family members involved. Should the woman referred to the hospital hide her new identity from those family members who have declined testing? Does she leave them to guess her test result

because of any risk-reducing surgery that she may or may not have had? Or, does she tell them and consequently pass on information about their own likelihood of having inherited the mutated genes, when they had decided not to know? Cox and McKellin (1999) furthered the argument, explaining that complexities can arise when the 'proband', defined as the first person to initiate contact with genetic services, has to decide if, when and how to inform family members. Hagoel et al (2000) also raised concerns that these family members might not be as emotionally prepared as the proband to face the repercussions of genetic testing, because they will not have undergone genetic counselling.

An important consequence of genetic medicine is that DNA testing enables one to learn about somebody else's future that they themselves may be unaware of (Everett, 2003). As such, the issue of genetic privacy creates conflict for both the patient and those implicated by the result. Novas and Rose contended that:

> the disclosure of genetic risk information gets framed in terms of the language of rights – the right to know – a right of one's kin, a right of one's children – the withholding of this knowledge is seen as an incursion on the right to choose. Yet…the right to know comes into tension with another right, the right not to know.
>
> Novas and Rose, 2000:505.

Similarly, Finkler et al (2003) asserted that whilst the person tested has the right not to share their genetic information or destiny, family members themselves have the right to remain unaware of their genetic fate should the person tested feel that they should be informed. However, the ethical dilemma is extended; the recent Government White Paper on Genetics, "Our Inheritance, Our Future" argued that if asked:

> under the Data Protection Act, a doctor or a counsellor is required to tell the relatives that information about them is recorded in the patient's medical records.
>
> Department of Health, 2003:78.

Informing a third party that information about themselves can be found in somebody else's medical records, infers that the third parties might themselves be at-risk. In such circumstances should a doctor act upon the obligation as outlined above in the White Paper? Summarising the dilemma that doctors may face, Kent argued:

> if I know something about myself does my brother or sister have the right to know it too, given that it also affects them? At what point is my wish to protect my own privacy over-ridden by their wish or need to know in order to avoid potentially harmful consequences?
>
> Kent, 2003:17.

The doctor may find himself in an ethically difficult position. Should he break a patient's confidentiality and pass on medical information to a third party, or should he keep the information to himself, knowing that the information he holds may affect the lives of others? Kent conjectured:

> there is no absolute right to confidentiality, but there is a widely held rebuttal presumption that information obtained in the course of a medical intervention will be held in confidence by the person who obtains it unless there is a very good reason for disclosing it.
>
> Kent, 2003:16.

However, The British Medical Association considered that, "health professionals have an ethical duty….to raise with patients the possibility of their information and choices affecting others" (1999:19). These arguments demonstrate that the advent of genetic medicine has created a novel challenge, which both doctors and patients must overcome.

In this chapter I focus upon the challenges presented to the traditional model of doctor-patient interaction by genetic medicine, and use data collected from one observation of a consultation. The question 'who is the patient' is addressed from a stance influenced by conversation analysis. By utilising such a viewpoint, it is possible to illustrate the accomplishment of social action via participants' interaction. An in-depth focus upon the turn by turn analysis of the participants' communication, or their 'talk-in-interaction' (ten Have, 1999) enables one to illustrate how each party constructs the identity of the 'patient' and produces their attempt to be seen as the 'patient'. A table of the conversation analysis notation used can be found in appendix five.

The following analysis concentrates upon a BRCA related consultation that took place in the Department of Clinical Genetics at Hospital X. At Hospital X, family members were invited to attend counselling sessions along with the individual referred. This

consultation involves five people: May, the woman referred, her eldest daughter Linda, Linda's husband Steven, the nurse, and the doctor. The group are discussing a family history of breast cancer, following breast cancers diagnosed in May's sisters, Freda and Jane, and her youngest daughter, Kate. The data excerpts analysed have been chosen with the aim of demonstrating the difficulties in identifying a sole patient. The argument for four individuals to be considered the patient is made, and I conclude the chapter with a brief examination of genetic exceptionalism in light of the data presented here.

i. Patient one: May.

May was nearing 60 years of age, and had been referred for genetic counselling by her general practitioner (GP). At the start of the consultation it is noticeable that the doctor only spoke to May when greetings and introductions were shared, and even asks May to sit closer to him. After a stalled attempt to start the medical aspect of the consultation by the doctor, during which the remaining parties seem unaware and continue with their own conversation, medical matters were finally dealt with when the doctor stated:

19 Doctor: Right (.) **Doctor J wrote to us** [
20 May: [yes
21 Doctor: I think initially you (.) weren't aware of that were you?

Consultation with May, lines 19-21; emphasis added.

As the data extract illustrates, May's GP had referred her to the hospital. May is the 'patient' that has been sent to the hospital. However, the aim of the consultation is to investigate the family's risk of hereditary breast and ovarian cancer, as illustrated in lines 31-32 (see overleaf). Thus in this data extract, May only occupies the patient role in an administrative sense.

Nevertheless, May did have a clinical 'need' that required her to visit her GP, which in turn triggered the referral to the hospital. However, in visiting her GP and requesting mammography screening, she did not expect to be sent to the Department of Clinical Genetics, or for her family to become involved. She clarified:

23 May: **All I went to see, when I went (1.0) err, to him, was**
24 **to ask if I could have a mammogram more than (.) once every**
25 **three year** (0.6).I never realised hhh that it was going to cause all
26 this trouble. Huh you know, I thought he'd just sort it out and tell
27 me yes or no.

Consultation with May, lines 23-27; emphasis added.

Following May's explanation of why she visited her GP, an action that allows her to be labelled as a patient, the focus of the consultation shifts. At line 31 (below), the doctor explains that whilst it is May who has been referred to the hospital, it is the family rather than the individual who will be investigated in this consultation. As such, the doctor is driving the definition of who the patient is, away from the individual towards the family. The doctor explained:

28 Doctor: I think its quite complicated, so, we are beginning to understand quite
29 a lot about, e:rm (1.0), genes and breast cancer, that's why he's
30 asked us to [
31 May: [I see, yeah [
32 Doctor: ['cos **we see quite a lot of families**
33 that are in a similar situation to your own [
34 May: [Yeah
35 Doctor: So (.) what we want to (.) um (.) start by doing, is just going
36 through some of the details again if that's okay.

Consultation with May, lines 28-36; emphasis added.

At this point in the consultation, May appears to comprehend that it is her family, not just herself who is implicated and consequently involved in the consultation. For example, following the doctor's statement, "we see quite a lot of families that are in a similar situation to your own" (lines 32-33), May utters "Yeah" (line 34), which is a response token (Gardener, 2001). Response tokens such as 'yeah', 'mmm', 'oh' and 'uh-huh' illustrate how talk is co-constructed between participants, one acting as the vocaliser and the other as the listener. By stating "yeah" (line 34), May demonstrated that she had heard the doctor's last statement, and is intimating that he should continue with his turn. Hence, almost immediately following the introductory section of the consultation, the focus on May as the patient has been diluted, and shifts to include additional people.

The stated aim of the consultation is to "go through some of the details again" (lines 35-36), and throughout the consultation it is May who is able to provide most of the details that the doctor requires. Thus, she is fulfilling a major patient role. May provides a competent medical history that will allow the doctor to perform his role.

May becomes the focus of the consultation and again lays claim to being recognised as the patient, when the doctor uses a chart to illustrate an individual's likelihood of developing breast cancer. The doctor stated:

535	Doctor:	…….if you are
536		thinking about yourself now ((cough)). If we think (.) about
537		((cough)) The chance of somebody, anybody in the general
538		population (0.4) without a family history of breast cancer,
539		and that would be a one in 12 risk which when you put it on
540		the chart comes down there. And what you notice is that the
541		older you get the more likely you are to develop breast
542		cancer. So those who include <u>clearly</u> a hereditary (1.0) err,(.)
543		component here.

Consultation with May, lines 535-543; original emphasis.

A marked feature of this section of the consultation is that the doctor only maps May's probability of developing breast cancer onto the chart that has been drawn (line 546 to 547). The doctor explained:

544	Doctor:	Not everybody gets it, sometimes it can skip (.) generations but
545		if you look at familial, if you notice they develop it earlier, (2.0)
546		and then say get the older, (1.0) it sort of lowers off. (.) So
547		what I've done is (.) **I've put this red line on - you're nearing**
548		**60 I think?**
549	May:	Yes, well, err, yes hhh
550		(inaudible)
551	Doctor:	Two or three year's time! Um, you'll be 60 - I've drawn it just
552		before 60 actually
553	May:	Right

Consultation with May, lines 544-553; emphasis added.

The doctor's decision to draw only May's likelihood of developing hereditary breast and ovarian cancer onto the chart might be considered surprising. May is nearing the age where the development of either cancer would be explained by normal population risk,

rather than her being at increased genetic risk of developing the disease[20]. However, her eldest daughter Linda, who is present at the consultation, and her youngest daughter Kate, who is not present, are at the age where the risk of developing early-onset hereditary breast cancer is at its highest, and so maybe could have expected to be included in this part of the consultation. Nevertheless, their risk of developing HBOC is not mapped onto the chart at any time in the consultation. This omission is significant, and suggests that the doctor may not perceive either daughter to be the most relevant 'patient' in the consultation at this time.

May's last contribution to be identified as the patient occurs within a shared discussion between the doctor, Linda and herself about the hereditary nature of BRCA genes. The doctor is discussing the likely pathways from which the gene might have been inherited. In the middle of this discussion, May asks a direct question, and appears to be trying to comprehend whether she or her husband could have passed a mutated BRCA gene onto their daughters. She initiates the question, and states[21]:

683	May:	Say me Mum passed it on to me [
684	Doctor:	[Yep, (3.0)
685	May:	= and I
686	Linda:	= and its gone through you to Kate
687	May:	Cos I mean, (2.2) their Dad died of cancer, so (1.4) **what I'm**
688		**trying to figure out is if, have I passed it on to Kate, or**
689		**would it have been her Dad's gene?**
690	Doctor:	I'd like to look into that in more detail, but the sort of cancer that
691		your husband had, erm isn't one that we usually see in families.
692	May:	**Yeah**
693	Doctor:	But it's not usually hereditary. I think from what you've described,
694		but I'll try and look into it in a bit more detail, but that wouldn't
695		bring in Freda's[22] gene then.
696	May:	**No, of course it wouldn't.**

Consultation with May and Linda, lines 683-696; emphasis added.

[20] Breast cancer linked to a BRCA mutation is characterised by its early-onset. Bennett, Taurog and Bowcock (1999) defined early-onset as below 35 years of age. Comparably, sporadically developing breast cancer, "is a typical disease of middle aged and older women. Approximately 4-8% of total cases occur in patients less than 40 years old" (Turchetti et al, 2001:283). Breast cancer linked to a BRCA mutation is characterised by its early-onset. Bennett, Taurog and Bowcock (1999) defined early-onset as below 35 years of age.

[21] This data extract has been published elsewhere. See Pilnick (2002a).

[22] Freda was one of May's sisters, who had previously been diagnosed with breast cancer.

By trying to determine who passed the mutated gene to her daughters, it is possible to argue that May is attempting to apportion blame and responsibility for Kate's breast cancer elsewhere. At line 687, May implies that her husband might have passed on the gene as he died of cancer. However, the doctor explains that her husband's cancer was not a familial type, to which May again uses the response token "yeah" (line 692). Upon receipt of this response token, the doctor continues his dialogue and a few turns later implies that should a mutated gene exist, it would most likely have been passed from May to her daughters. In the following turn, May concedes that a mutation passed from her husband's side of the family would not account for her sister's breast cancers (line 696). Although the doctor is careful not to apportion blame or responsibility for a positive BRCA mutation to May, it becomes clear that she is most likely to be the parent carrying a mutated gene. Consequently, it would be understandable if she were to inhabit the patient role again. However, May's only other role in the remainder of the consultation is as a storyteller of the family's illness experiences.

In view of the data that has been discussed in this sub-section of the chapter, can May be considered to be <u>the</u> patient? She inhabits many roles in the consultation, and more importantly, is the individual who was referred to the hospital. She has her own information needs and uses the consultation to successfully meet these. However, whilst she might be recognised as the patient because she was the first point of contact, the aim of the consultation was to investigate genetic risk. To echo the suggestion made by Pilnick (2002a), Hallowell (1999) and Armstrong et al (1998), genetic medicine extends the medical gaze and focuses upon the family not just the individual. Given her age, May therefore does not present a strong enough case to be considered as the 'patient'.

ii. Patient two: Linda.

If May is not the most significant person to inhabit the patient role in the consultation, then might it be Linda? Linda was 35 years old and presented at the consultation with her mother and husband.

In the first section of the consultation, (not reproduced here) the researcher and doctor are introduced and May talks about her health. Linda plays little part in the interaction other than interjecting with short responses to support her mother's utterances. She

develops her participation in the consultation and becomes the focus of medical inquiry when the doctor asks about her illness history (lines 122 to 217). Although only a small section of the dialogue is presented in a matter of 26 lines, Linda imparts a large amount of information, which enables her to be seen as constructing her claim for being recognised as the patient.

In opening the dialogue, the doctor enquired about her current health:

122	Doctor:	And in your (.) erm, yourself?
123	Linda:	Yes hhh. Apart from suffering panic attacks [
124	Doctor:	[because of all
125		this in the family or
126	Linda:	Well, I don't know, but um, (.) I was there when me Mum rang
127		up and told me about our Kate last night, that caused an attack
128		straight away, as soon as me Mum told me. Um (.) when, she
129		first rung up and told me that she had cancer I had an attack
130		then, but I'd had an attack sort of previous to that, so I don't
131		know (.) I won't say it's the actual cause
132	Doctor:	Do you examine your (.) own breasts? (0.6)
133	Linda:	I do now hhh. I didn't sort of used to before this, but since
134		this scare with Kate, yeah, yeah
135	Doctor:	And um [
136	Linda:	[actually (.) I went to see my doctor about it; told my
137		doctor and she sent me for a mammogram
138	Doctor:	Yes
139	Linda:	and unfortunately I caught flu and so I couldn't go and so I
140		rang the hospital and they said they'd send me another
141		appointment and they never did, they never got back to me
142	Doctor:	Oh right, well I'll sort you out then (1.0)
143	Linda:	Oh yeah, and they were going to send me another
144		appointment but they never got back to me [
145	Doctor:	[right
146	Linda:	And I went another time didn't I and there was something
147		wrong with it (1.0)

Consultation with Linda, lines 122-147.

What is interesting about this excerpt of the consultation is the manner in which Linda's turns dominate the interaction with the doctor compared to the extent of those made by her mother in her interaction with the doctor. In direct contrast to the brevity of May's responses, Linda's replies to the doctor's questions are comparatively lengthy and contain a great amount of medical information upon which the doctor is able to respond.

Linda constructs her occupancy of the patient role by reiterating her concerns regarding the cancellation of her mammography appointment (lines 136-41, 143-144; 146-147). This prompts the doctor to arrange for another appointment to be made (line 142). However, at line 145 the doctor repeats his acknowledgement of Linda's utterance, stating "right". Nevertheless, Linda continues with her request, despite the doctor's earlier statement (line 142) illustrating his agreement to arrange a mammography for her. As such, this excerpt of the consultation demonstrates how Linda ensures that her risk of breast cancer remains the focus of the consultation.

Whilst Linda continues to hold the position of the patient within the consultation, the line of medical investigation alters. The doctor questions Linda about her medical history. Linda responds, reporting upon her experience of being diagnosed with a malignant lump in her neck, and an in-patient stay because of a road traffic accident. It takes some 70 lines further into the consultation before the issue of breast cancer is broached again, with the doctor repeating his question about whether Linda practices breast self-examination. Linda replies negatively, and the doctor offers to provide her with some reading material so that she can become informed about the technique. Despite Linda's negative response, the focus of the consultation shifts to focus upon her children. It subsequently becomes clear that Linda has two agendas for presenting at the consultation. She wants to manage her own risk, but also wants to become aware of the threat that her daughter faces. She explained:

262	Linda:	Well, **that's why I wanted to come really**, 'cos she's you know	
263		(.) my daughter =	
264	Doctor:	= she's 14 and we really need [	
265	Linda:		[right
266	Doctor:		[to think about her future
267		as well	
268	Linda:	Right	

Consultation with Linda, lines 262-268; emphasis added.

This extract of the consultation illustrates that Linda has presented at the consultation as a patient who is in need of medical intervention (mammogram) and who may also be at-risk of HBOC, as well as a worried parent whose daughter may likewise have inherited a mutated BRCA gene.

Linda constructs her right to the occupancy of the patient role more comprehensively than May's attempt. Her agenda for the consultation, and the requests that she makes result in her domination of the encounter. In comparison, May did not really appear to comprehend the extent of her family's risk, and thus the reason for the party's attendance. Moreover, it is important to acknowledge the significance that may be inferred from the presence of Linda's husband. This suggests that Linda's attendance at the consultation may be more significant than just as a support for her mother. Rather, it is possible that she feared that either she would need some emotional support herself, or felt that her husband should also be aware of any possible risk to their daughter. As a result of the consultation, Linda receives the mammogram that she wanted. This confirms that she is a patient with a relevant clinical need. However, more significantly, her entire family will be placed on the family history register and will be monitored. This action reduces the attention on Linda, and places it upon her family.

As a result of her sister Kate's early-onset breast cancer, in addition to the breast cancers of her maternal aunts and the ovarian cancers of her maternal and paternal grandmothers, Linda would be labelled as being at high-risk of developing an inherited form of either disease. Consequently, Linda would be considered an ideal candidate for genetic testing, and thus could expect to be recognised as 'the patient'. However, testing is not carried out on pre-symptomatic people because of the difficulty and associated expense in searching for a mutated gene. Locating a positive gene has been likened to finding a needle in a haystack (Parsons et al, 2000). Linda's only hope of undergoing genetic testing, and again entering the patient role, relies upon her sister. Kate could either undergo genetic testing herself, or she could provide a blood sample that would be tested for a mutation. If Kate chose the second option, she would not be told the result. If a positive test result were returned, either of these actions would however, enable Linda to take steps to discover if she carried a genetic mutation.

iii. Patient three: Kate.

May's youngest daughter Kate developed breast cancer in her late 20s. She underwent a mastectomy and prophylactic oophorectomy. She did not attend the consultation with her mother and sister.

Although Kate has not undergone genetic testing herself, she would be an ideal candidate should she choose to discover if she carries a mutated BRCA gene. Unlike her aunts who developed breast cancer in their 50s, Kate's cancer was characterised by its early onset. Therefore, regardless of her absence, she is an important party in the consultation. However, whilst she could have genetic testing, from the account given by May and Linda it appears that not only does she not wish to investigate her risk any further, but that she wants to "forget" about it (lines 864 - 865). Consequently, she is reported to have decided to relinquish any right that she may have to inhabit the patient role:

863	Nurse:	May was just saying that Kate doesn't like talking about it
864	May:	No, I think she's been through that much that she just wants to
865		forget it
866	Linda:	It's scary isn't it
867	Nurse:	Well, let us know when it's appropriate, won't you, when it's all
868		the right to talk to her, obviously if she's unwell, if she's
869		bleeding at moment then its not the right time, but
870	May:	Yeah
871	Nurse:	If there becomes a time when you are able to talk to her, I am
872		happy to go and see her at home
873	May:	Yeah, yeah
874	Nurse:	And that won't be to do anything awful; if she wants to give a
875		blood sample and
876	Linda:	Well, she's made a good recovery, but as I said, she's that fed
877		up.

Consultation with May and Linda, lines 863-877.

With Kate's apparent refusal or reluctance to undergo genetic testing, Linda and any other member of the family are denied the opportunity to have testing themselves. Finkler et al explained:

> in order for the physician to make a diagnosis, various family members must be involved.

Finkler et al, 2003:409.

Given the significance of Kate's involvement in the family being able to undergo genetic testing, the nurse continues to suggest ways in which Kate could become involved. She explains that Kate would be under no pressure to attend the clinic, and any contact could wait until it was the right time (lines 867-869). As I discussed

previously, should Kate choose not to undergo genetic testing herself, she could provide a blood sample that would allow Linda to have testing. While this would enable Linda to inhabit the patient role, it would create an ethical dilemma, which I outlined earlier in the chapter. Genetic information provides information about one's biological relatives. By having Kate's blood sample tested, Linda could discover if she would be eligible to undergo genetic testing herself. If Kate's sample tested positive for a BRCA mutation, the same genetic abnormality could be searched for using a sample of Linda's DNA. Should such a scenario arise, Linda would be aware of her sister's mutation carrier status when she (Kate) was not. Moreover, should Linda be tested and found to carry a positive mutation and consequently decide to have risk-reducing surgery, Kate would be able to deduce her own carrier status from her sister's actions.

iv. Patient four: Sharon.

Sharon is 14 years old, and Linda's only daughter. She was not present at the consultation.

As I discussed earlier, one of Linda's stated agendas for participating in the consultation was to discover whether her daughter might be at-risk of HBOC. Such an agenda demonstrates that Linda realises that the scope of the medical gaze will not just fall upon individual members of the family, but will be extended to encompass all of those that might be at-risk. Consequently, her account of her attendance is structured to emphasise that she considers that it is important that the potential risk to her daughter is recognised.

Whilst it is possible that Sharon may have inherited a mutated BRCA gene from her mother, which in turn, would depend upon Linda carrying a mutated gene herself, she would not be invited to see the doctor at such a young age. I observed many similar cases during the time I spent 'in the field' at the Family History Clinic. For example, one comment was, "obviously your two daughters are 20 years away from us even wanting to have a family history chat with them" (Consultation with Wendy, lines 83-84) [23]. Women at-risk of HBOC asked clinic staff about the risk to their children, and

[23] Wendy's daughters were four and seven years old.

were told that any children would not be offered genetic testing until they reached their mid-20s. This age limit was rationalised as the clinic staff felt that no effective prevention strategy could be offered before they reached this age. Therefore, although Sharon may be at-risk, she would not be offered genetic testing. Rather, her details would be recorded and she would be invited to the clinic and to undergo screening during her 20s.

5.2. Who is the patient? An exceptional problem?

The availability of genetic tests has heralded a change in the medical relationship. Finkler argued,

> the foreseeable consequence of the medicalisation of kinship for all of us is that people may no longer need to present complaints to be regarded as sick. They may be considered sick simply because they come from families with particular diseases.
>
> Finkler, 2001:244.

Consequently, "persons could be designated patients in an anticipatory sense" (Jonsen, 1996:8). Throughout this chapter, the cases of four individuals, each of whom might legitimately be considered to be the patient, have been discussed.

May was at the age where a breast cancer diagnosis would normally be explained as sporadic opposed to genetic (Love, 1995). Moreover, she is not the person who would be taking the genetic test. Consequently, although May is the primary focus of the medical gaze for a large proportion of the opening section of the consultation, when compared to conventional expected roles in the consultation, she is not the patient. Rather, she is the storyteller, or gatekeeper to the family's disease history, including the cancers of her sisters and parents, opposed to a patient who has a clinical need that is relevant to this consultation[24]. Therefore, in a genetic sense, it is possible that May is not the most significant 'patient' attending the consultation.

[24] As discussed previously, May's clinical 'need' was for further and more frequent mammography screening. However, the aim of the consultation was not to arrange this, but to investigate the family's risk of HBOC.

Secondly, I addressed the case for Linda to be recognised as the patient was addressed secondly. Linda was in the age range where HBOC might be expected to develop. She attended the consultation with her own agenda; she wanted to be aware of her risk and receive mammography screening. However, like May, Linda would not be the individual who would undergo genetic testing in the first instance. For Linda to have testing, her sister would need to test BRCA positive. Following this, Linda would subsequently be offered testing.

Therefore, although she did not attend the consultation, Kate is the most significant person whilst examining this family's risk of developing HBOC: she has had early-onset cancer. However, the account given by her mother and sister appears to suggest that she is refusing to investigate whether she carries a genetic mutation. The opportunity for the family to discover their genetic risk is therefore dependent upon Kate donating a blood sample.

Lastly, the case for Sharon to be considered as the patient was examined. Whilst she may have inherited an increased risk of HBOC from her mother, she was too young to meet the hospital's referral criteria.

This chapter has demonstrated how the difficulties and uncertainties associated with deciding who should inhabit the patient role, present a challenge to the medical. Within the genetics consultation, it is impossible to define 'the patient' as just one individual. Rather, there is "one primary [patient] and two secondary [patients]. The primary [patient] is the woman who makes the genetic clinic appointment. The secondary [patients] are the family as an entity and other members of the family as individuals" (Kenen et al, 2003b:859-860). Consequently, Novas and Rose suggested that:

> the illness or condition becomes a 'family' matter. The 'cause' of the patient's problem might be a family member in a previous generation; the diagnosis in one person has all kinds of implications not only for themselves but also for their relatives.
>
> Novas and Rose, 2000:490.

However, there are examples of non-genetic therapeutic relationships in which it is difficult to pinpoint whom should be identified as 'the patient'. The distinction of whom

the patient is, is also less than clear when discussing the child-parent-doctor relationship (see Strong, 1979), and away from the field of human medicine, in the owner-pet-vet relationship. Nevertheless, in all of these cases, a diagnosis will ultimately be made and one party in the triadic relationship will receive treatment, and become the patient. Therefore, a qualitative difference does seem to exist between genetic and non-genetic consultations.

Further still, while the results of genetic tests can affect members of the wider family, so too can other diagnostic tests (Green and Botkin, 2003). Green and Botkin cited examples such as the papanicolaou gonorrhoea smear and the tuberculin skin tests, to argue that the results of these tests also implicate others. Consequently, they suggested that "the introduction of predictive genetic testing into medical practice does not…..introduce any novel ethical dilemmas" (Green and Botkin, 2003:573). However, genetic mutations such as BRCA1 and BRCA2 are inherited along a vertical line of transmission, passed from parent to child at the time of conception. Tests such as those outlined by Green and Botkin investigate diseases that are transmitted through exposure to an infected individual. Consequently, there is a difference between biological and infective transmission of disease.

Whilst the involvement of third parties in an individual's medical care is not a novel development, the differences between the modes of transmission does seem to infer some level of exceptionalism. Although the difficulties in identifying the patient may not be a challenge unique to consultations with women at-risk of HBOC[25], it is certainly not common practice. Murray's (1997) argument that genetics is exceptional is therefore given support, albeit in a limited manner.

In concluding this chapter, I suggest that the data I have discussed supports Katz Rothman's contention that the development and rise of genetic medicine has opened up a "troubling can of worms" (1998:151). I propose that the development of genetic medicine has created challenges that the medical profession and wider society must react to. The new technologies have led to problems at an individual level, where people

[25] For example, the issues of live organ donation and the birth of donor babies raise similar issues. Donor baby is the term given to foetuses that are created using IVF and are then tested, using pre-implantation genetic diagnosis, to tissue match an unwell sibling. Following the child's birth, stem cells can be harvested from the umbilical cord, and transplanted into the unwell child.

can struggle to come to terms with their new, or revealed genetic identity (Armstrong et al, 1998). Moreover family secrets can be uncovered. Genetic medicine has provided challenges at a structural level too. Medical services have developed to meet the technological challenges presented, yet as I discussed in chapter one, current the demand for these services outweighs the provision. Lastly, at an interactional level, further problems remain. As I have illustrated in this chapter, difficulties continue to prevail whilst establishing whom to identify as the patient in a genetic consultation.

In chapter six, I continue the examination of the consultation, and question whether genetic medicine has challenged the existing sociological models of the doctor-patient relationship.

Chapter Six. The Doctor-Patient Relationship.

> Patient-practitioner relationships are best viewed in the framework of social roles, of the attitudes and activities the two parties bring to the situation of care. This interaction of two or more persons, centring around the health needs of a single individual, is far from being a spontaneous happening. It is, rather, a more or less well-rehearsed confrontation in which the key participants have learned to expect certain things and to act in certain ways.
>
> Wilson, cited in West, 1984:16.

In this chapter I build upon the foundations laid in chapter three, and analyse data collected from observations of consultations and accounts given by the women during the interviews in relation to the style of doctor-patient relationship that was experienced.

The majority of the data analysed in this chapter derives from consultations held in the Family History Clinic at Hospital X. One further consultation features an encounter that occurred at the Department of Clinical Genetics also at Hospital X, which was kindly provided by Dr Pilnick from her data archive. I illustrate the difficulty in attempting to establish which format of doctor-patient relationship is practiced within these consultations, and conclude with a discussion of whether a new, distinct model of the doctor-patient relationship is required to react to the challenges that genetic medicine presents to the traditional model of medical enquiry.

6.1. The consultation.

Six different doctors and one nurse were mentioned by the women who participated in the interview phase of this study. These two additional doctors are not included in the sample profiles. No analytical argument is made regarding the identity or professional rank of each doctor, thus all data is anonymised to 'doctor'. In instances were women have identified the doctor within the data extracts utilised, the doctor's name has been further anonymised to the pseudonym of Doctor A, B, C, D, E, F, G or J[26]. The suffix given to each doctor remains constant throughout the thesis.

[26] I have chosen to use this strategy, as I do not wish that any inference should be drawn from the women's accounts of their doctor. Profiles of the doctors, the breast care nurse and the patients are provided in Appendix two.

Wendy, Caitlin and Laura had been diagnosed with a malignant tumour prior to their referral to the Family History Clinic. The remaining women were asymptomatic, although it is unknown whether they had any cancerous cells in their bodies. Therefore, the majority of patients participating in this study were not responding to their symptomatology and seeking medical advice. This description thus places the traditional doctor and patient roles as outlined by Parsons (1951) in turmoil. The patient is not 'ill', and consequently, the doctor is unable to return them to health. The patients were at-risk, and sought referral to explore their risk of developing HBOC. Within the consultations discussed in this chapter, the doctor's role is to inform the patient so that she (the patient), can reach a decision regarding whether to undergo genetic testing and, should a positive test result be returned, consider risk-reducing surgery. It is the ensuing doctor-patient relationship, and in particular, the manner in which the doctor informs the patient, and how the patient is included within the consultation, that I examine within this chapter.

Whilst the consultations were not genetic counselling sessions, research has shown that genetic counselling encounters differ little from other medical consultations (Pearce, 2004). However, women attended the consultations to discuss genetic related issues, and therefore the following discussion draws upon this body of literature.

Genetic counselling entails the patient comprehending the relevant medical facts and risk management options related to their condition. Patients should leave the consultation with, 1) an appreciation of the hereditary nature of disease, 2) an understanding of the available risk management strategies, 3) the option to make a decision about testing and risk management, and 4) the ability to make an appropriate adjustment to their new identity as a carrier of a positive BRCA mutation.

A central tenet of genetic counselling as a communicative process, is the provision of objective information passed from the doctor to the patient (Marteau and Richards, 1998). It is considered that doctors should aim to give patients enough information to enable them to make a decision wisely, rather than a wise decision (Elwyn et al, 2001). However, placing such an obligation upon a doctor can create a problematic and paradoxical relationship between the doctor and their patient. Freidson argued, "the separate worlds of experience and reference of the layman and the professional worker

are always in potential conflict with each other" (1975:286). Hence, within genetic medicine the conflict between doctor and patient may arise because the patient's wise decision, or the decision she makes wisely, may clash with medical opinion regarding the most appropriate way in which to manage genetic risk. As a result, the doctor may feel that the patient has reached the wrong decision and is not managing their risk in the best way. However, Clark et al (2000) proposed that doctors ought to take a non-judgemental approach regarding any decisions or outcomes that the patient chooses. In doing this, the information provided by the doctor should be neutral and impartial (Van Zuuren, 1997) and the consultations should be client-centred. Consequently, genetic counselling epitomises the ethos that patients ought to make their own decisions, as they alone know their feelings and beliefs better than anyone else. Moreover, it is the patient who has to live with any consequences of their decision.

Whilst contemporary medical practice advocates the involvement of the patient, the patient was previously perceived to be "incompetent to judge what is needed and in order to be cured must put himself passively into the hands of the staff, obeying them without question and allowing them to do to him what they see fit (Freidson, 1970:133). However, as implied above, the claim is increasingly being made that medicine has again become patient-centred[27] (Stewart et al, 1995; Edwards and Elwyn, 2001), and patients are being invited to participate in treatment decisions.

However, decision-making may be problematic and difficult for women at-risk of HBOC. Uncovering a person's BRCA status does not carry an automatic benefit in itself. Van Zuuren suggested, "instead of offering the certainty longed for, the information provided during genetic counselling will often be full of uncertainties" (van Zuuren, 1997:130). A positive test result will inform the patient that she has an increased risk of cancer, but it will not disclose with any certainty if, or when she might develop the disease, and whether it will manifest as breast or ovarian cancer, or indeed as both.

[27] Most notably, the patient had been a central focus of the medical encounter during the era of bedside medicine (Armstrong, 1979). As I discussed in chapter three, the diagnosis and treatment path followed by the doctor was influenced by the patient (the patron). The doctor's salary and continued employment was dependent upon the patient satisfaction with the services provided by the doctor. Thus, it was in the doctor's best interests for the patient to feel that their concerns and needs were of paramount importance to the doctor.

The uncertain nature of being at-risk is extended whilst discussing the effect of being offered a choice of surgical procedures for the treatment of breast cancer. Fallowfield et al reported that women had difficulty making treatment decisions, and described how, "23 of the 62 women who were offered choice found it difficult to make a decision; 8 refused to choose" (1994:448). However, such a 'failure' to reach a decision is not unusual, nor indeed does it signify a patient refusing to participate in decision-making (Coulter, 2002). Baum et al rationalised:

> a significant minority of women prefer the decision to be taken by the doctor and therefore true autonomy means permitting the patient's option of delegating the choice to the surgeon.
>
> Baum et al, 1988:1452.

Therefore, while some women are happy to make decisions either by themselves or in collaboration with their friends and relatives (Clark et al, 2000), others prefer not to make a treatment decision and defer to the doctor. However, these patients are not refusing to make a decision; rather, they have chosen to relinquish control and place it in someone else's hand (Shiloh, 1998; Coulter, 2002). Consequently, it can be argued that they are still exercising their autonomy (Beaver et al, 1999).

Patients' desire to participate in decision-making is also influenced by the perceived severity of the condition and the likely outcome of any treatment chosen. Edwards et al (2003) reported that patients were more likely to participate in decision-making when the condition was not life threatening. Therefore, it is possible that the decision-making process of women at-risk of HBOC may differ from the decision-making process of women diagnosed with breast cancer. Women at-risk of HBOC do not face an immediate threat to their lives, unlike that experienced by women diagnosed with stage four breast cancer. Fallowfield explained:

> it seems, on balance, reasonable to argue that the perception of healthy individuals about their desire to participate in decision-making should they develop breast cancer, bears little resemblance to those of people confronting a life-threatening disease.
>
> Fallowfield, 1997:211.

In addition to the significant developments in genetic medicine, the move towards patient participation and patient-centred medical approaches has altered the traditional roles of the patient and the doctor. Fallowfield (1997) conjectured that such changes in social attitudes towards medicine have created a consumer–culture, whereby patients want and demand greater levels of information from their doctors. However, whilst Hallowell (2000) wrote of women playing an active role in regaining control of their dangerous bodies, Fallowfield (1997) found that patients with breast cancer seemed happier to share decision-making with experts, or take a more passive role compared to the active role performed by health professionals, an activity which appears to clash with the goals of a consumer led medical relationship. Such differences in the participation level of women led Beaver et al to state:

> active engagement in decision-making is not a role that all patients feel comfortable adopting, and certainly for women with breast cancer…the doctor has been the preferred as the primary decision-maker.
>
> Beaver et al, 1999:267.

Women vary in the level of involvement they wish to have in the clinical decision-making process. The doctor-patient relationship must therefore be able to react to such variation.

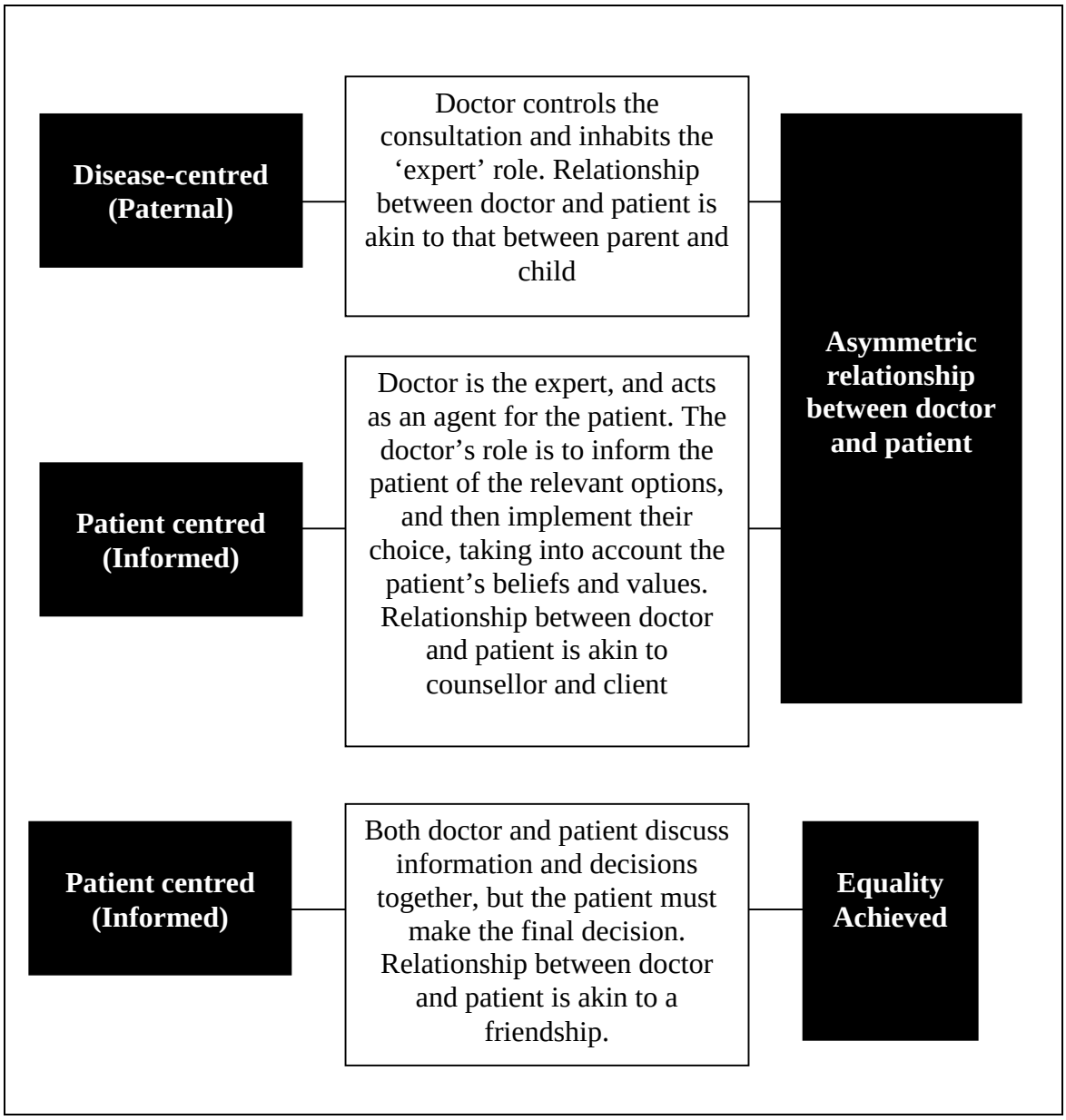
6.2. Models of the doctor-patient relationship.

In chapter two I discussed how previous studies examining women's experience of being at-risk of HBOC have concentrated upon outcome measures such as the patient's satisfaction with the consultation (Shilling et al, 2003), anxiety levels (Thirlaway et al, 1996) and information needs (Meredith et al, 1996; Hallowell et al, 1997). Other authors have focused upon the relationship developed between the doctor and the patient and have examined the style or format of the encounter followed (Ford et al, 1996; Charles et al, 1998; Gafni et al, 1998).

Charles et al (1997) proposed that three models of decision-making within the doctor-patient relationship predominate; the paternal model, the informed model and the shared model. Although labelled differently, these models concur with the sociological models

of doctor-patient interaction that I discussed in chapter three and around which this chapter is structured. Figure 17 depicts each of these models, and illustrates the synchronicity between the models that Charles et al proposed and those which I use in this thesis.

Figure 17: Popular models of doctor-patient interaction.



In composing the above chart, I was influenced by much of the existing literature (Szasz and Hollender, 1956; Emanuel and Emanuel, 1992; Charles et al, 1997). However, upon commencing data analysis I quickly came to realise that the existing characteristics

summarised in the middle boxes of figure 17 required some updating in order to describe the doctor-patient relationship reported by women at-risk of HBOC.

The following discussion of the doctor-patient interaction emphasises the role of the doctor and the patient within the consultations. However, they were not the only parties in the consultation room. In all cases observed, a nurse was also present, yet she was given no opportunity to verbally participate in the consultation. The nurse's attendance can therefore be described as an absent-presence. Given the emphasis that has been placed on a team approach to the provision of medical care (English, 1997; Cort, 1998; Smith, 1999; Firth-Cozens, 2001) and the notion that "teamwork is crucial for the delivery of good quality patient care" (Firth Cozens and Moss, 1998:1335), the absent-presence of the nurse within the data is surprising. Therefore, in the following analysis, it is not that I have overlooked the contribution of the nurse in the development of the interaction. Rather, the nurse was sidelined as the doctor took the central role in the medical team.

i. The disease-centred model of doctor-patient interaction.

The disease-centred model of the doctor-patient relationship is doctor-centred and based upon the premise that "only the doctor [is] sufficiently informed and experienced to decide what should be done" (Coulter, 2002:34). The model places an obligation upon the doctor to ensure that the patient receives appropriate care and treatment to alleviate their symptoms. The patient's only role within the encounter is to consent to treatment. The doctor makes the decision regarding which treatment regime to follow. Moreover, this decision is reached in accordance with his or her own beliefs regarding what is in the patient's best interest (Szasz and Hollender, 1956). Consequently, the model is characterised by its paternalism and mashes with the traditional medical sociological role formats that Parsons (1951) utilised.

Coulter argued that although paternalism "has had its day" it continues to be the defining characteristic of UK health care (2002:xii). However, examples of a truly paternalistic relationship were lacking in the data collected, replaced instead by examples of patient deference towards the doctor. Not only were doctor portrayed as the only person sufficiently informed to be able to make the decision, but patients actively

chose to follow the doctor's advice. Joanna described her perceptions of the doctor. She stated:

79 Joanna: One assumes that one is dealing with people who are **experts**
80 in their field and who **know what they are doing**.

Joanna, interview, lines 79-80; emphasis added.

Like Joanna, Trisha made a similar comment, and described the doctor as an expert. She explained:

368 Trisha: He is the expert, you know, so you've got to play into his hands.

Trisha, interview, line 368.

As the two previous data extracts demonstrate, both Joanna and Trisha described their doctor as an "expert". In constructing their accounts so that they would appear to have deferred to the doctor, both Joanna and Trisha were ensuring that they would be recognised as respecting the doctor's greater knowledge, understanding and expertise. However, this does not mean that these women were acting passively or submitting to the doctor, as might be expected from a patient involved in a paternalistic style of medical interaction (Shiloh, 1998; Beaver et al, 1998; Coulter, 2002). Likewise, neither does it illustrate that the consultation is asymmetric. Rather, the women chose to defer to the doctor, having listened to his advice and made a rational decision to act in such a manner. Considering this, in addition to the lack of any examples of truly paternal, disease-centred medical practice in the data, it would seem that Coulter's insight that "paternalism has had it's day" (2002:xii) can be corroborated.

ii. The patient-centred model of doctor-patient interaction.

The patient-centred model of doctor-patient interaction calls for the doctor to act as an agent for the patient (Gafni et al, 1998). Using his expert knowledge, the doctor is obliged to inform the patient of the relevant treatment options available to them, and should implement the patient's subsequent decision. Emanuel and Emanuel explained, "the physician does not dictate to the patient; it is the patient who ultimately decides which values and course of action best fit who he or she is" (1992:2222). Thus, the

patient is instructing the doctor, and becomes the central figure in the decision-making process.

Central to the ethos of patient-centred medicine and the right of the patient to be able to choose whether to participate in the decision-making process, is the provision of information from the doctor to the patient. Gravois Lee and Garvin considered that information transfer involves one person performing, "a monologue and implies that the provider can exercise power over the receiver" (2003:451; original emphasis). Consequently, physicians can actively construct patients to be passive depositories of information (Gravois Lee and Garvin, 2003). The majority of the data that I collected from the consultation observations depicted a one-way flow of information, travelling from the doctor to the patient and thus supported Gravois Lee and Garvin's argument.

For example, whilst discussing Wendy's genetic risk, the doctor explained:

51	Doctor:	To start with, genetic testing – it's more in your favour that we
52		wouldn't be able to find a BRCA mutation. There are two of
53		them that we currently test for. But **looking at your**
54		**family history, you and your sister are the only ones to**
55		**get it at a young age and many others haven't.** There are
56		other gene clusters, other than BRCA which may explain why
57		some people develop cancers whilst others don't. But I'm not
58		saying that they wouldn't be able to find anything – it's a bit
59		more than bad luck.

Consultation with Wendy, lines 51-69; emphasis added.

At first, the doctor can be seen to be participating in a patient-centred model of medical interaction, as he starts his information giving by introducing the topic of genetic testing (line 51). However, the information giving is curtailed; he does not explain what is involved in the process of undergoing genetic testing, as might be expected in such a situation. Instead, he proceeds to the conclusion that "looking at your family history, you and your sister are the only ones to get it [breast cancer] at a young age and many others haven't" (lines 53-55). In this short extract, the doctor fails to provide the patient with the information that might be expected, and also appears to have reached a decision about the patient's lack of suitability of genetic testing based on disease-

centred criteria. Such action clashes with the central characteristic of patient-centred medicine that it should be the patient who ultimately decides upon their treatment.

Throughout Wendy's consultation, the information giving appears to be rushed when compared to that observed in other consultations, and the patient herself does not to take a central role in the ensuing interaction. However, whilst the doctor fails to elaborate upon his information giving, the patient does not attempt to question the information that she has and has not received.

In line 60 of the consultation, the doctor asks the patient a question, "have you thought about genetic testing?". However, by swiftly continuing his information giving, the doctor has denied the patient the opportunity to respond.

60	Doctor:	**Have you thought about genetic testing? There**
61		**are issues of family history for your inherited risk other**
62		**than breast cancer or if you carry a mutated BRCA gene,**
63		**then there is a predisposition to ovarian cancer.**
64		**Prophylactic surgery does increase the risk of not dying**
65		**from cancer. At your age it is extremely unlikely that**
66		**prophylactic surgery will influence your life expectancy**,
67		however, it is still good to stop further cancers, but it will not
68		make you live longer.

Consultation with Wendy, lines 60-68; emphasis added.

The data extract demonstrates how, following his question that is directed towards the patient, the doctor quickly continues with his information-giving monologue, seemingly hurrying through the risks of ovarian cancer and the possibility that the patient might choose to undergo prophylactic surgery. The doctor's behaviour, whilst appearing to be good practice in that he is providing the patient with information that will enable her to make a decision, is problematic when measured against the notion that the information should be extensive enough to be able to lead to a medically informed decision, as there appear to be gaps in the information provided.

Moreover, whilst the doctor does not offer any clarification of the information he has provided, he does offer his opinion about the patient's suitability for genetic testing and likely benefit from risk-reducing surgery. He states, "it is extremely unlikely that

prophylactic surgery will influence your life expectancy" (lines 65-66). Earlier in this chapter, I drew attention to the argument that information given during genetic consultations should be neutral, objective and value-free. However, the doctor's decision to voice his opinion could affect the decisions that the patient subsequently makes, and thus is at odds with the ethos of patient-centred medicine.

The objective of information transfer is to ensure that the patient has ample information in order to make an informed decision. Central to this notion is the belief that informed consent should be reached via full understanding of the relevant facts. However, the previous two data extracts lead me to question whether the patient left the consultation with adequate information in order to make her decision, especially as the doctor appeared to emphasise the inability of prophylactic surgery to increase her life expectancy (lines 65-66), the uncertainty related to whether her cancer could be accounted for by a genetic mutation (lines 53-59), or discuss genetic testing and her risk of ovarian cancer in any depth (line 63).

When I interviewed Jade, she mentioned a similar example of how the information transfer was rushed and how she did not receive as much information as she had hoped for. She described her consultation and recalled:

275 Jade: It was quite rushed and he didn't really give me much
276 information really.

440 I was quite scared wasn't I, because he, he never really said
441 anything positive.

Jade, interview, lines 275-276 and 440-441.

Jade's account is structured to emphasise that she believed that she did not receive sufficient information and left the consultation feeling anxious. Data collected from my observation of her consultation corroborates Jade's account. In outlining his agenda for the consultation, the doctor stated:

43 Doctor: We'll go into a bit more detail and in more time another time.
44 We'll do a breast examination today, and then arrange another
45 appointment for in a year's time, as there is no dramatic rush to
46 see you, and then we can talk about the longer term.

Consultation with Jade, lines 43-46.

Following his statement that "there is no dramatic rush" (line 45) the doctor appeared to hurry through the consultation, asking Jade if she was married, how she felt about being at-risk, whether other relatives had had breast cancer, and whether she was taking any contraceptive medication. The doctor then terminated the consultation, stating, "well, it's a really busy clinic. I usually go into more detail, so we'll rearrange the appointment for you, and just carry out a breast examination" (lines 77-79). The doctor did not provide any comprehensive information that would enable the patient to leave the consultation feeling fully informed and able to make a knowledgeable choice, and thus failed to address a central component of patient-centred medicine.

Moreover, although he asked how she felt about being at-risk, the doctor did not attempt to reassure Jade following her cautious response that she felt "fine, well, just from talking to [another] doctor really" (line 53). Rather, his comment that, "it's all ad hoc really, different places recommend different things, and opinions change with every patient" (lines 54-55) may have actually increased her anxiety. Data collected in other observations of consultations demonstrates that doctors endeavour to provide patients with the clinically required information, as the following extract between Susan and her doctor demonstrates.

During his consultation with Susan, the doctor provided a large amount of information about genetic testing. As the extract below exemplifies, the doctor participates in a one-way flow of information, which outlines the advantages and disadvantages of undergoing mutation testing. The aim of this information transfer is to enable Susan to decide whether she wishes to undergo genetic testing to detect whether she carries a positive BRCA mutation.

Susan: I think I need to know if I've got the gene before I can make any decisions.

Doctor: Well, you can make decisions without knowing if you carry the gene, but they are not as informed. Testing gives you information, but it is a big step and there is no way back from it. Issues you need to consider are that you can make decisions without information - you can choose to do nothing, have screening - you're probably high risk enough that should a hormonal test be developed in the future, that it would fit in with your family history. Without definitive evidence though, I don't think anyone would agree to carry out surgery on you. You could have the test, join studies if they are available or make a blind decision, but there are no implications about whether you have the gene. Really, it's like a flip of a coin - you either have the gene or you don't. You need an informed approach - if you don't carry the gene, then you have the same population risk as anyone else, and you don't need to consider treatment.

Consultation with Susan, lines 4-21.

As the extract demonstrates, the doctor imparts a large amount of information. He emphasises that Susan should take "an informed approach" (lines 18-19), because once she has had genetic testing, "there is no way back" (line 8). The doctor provides the information that he believes to be the most useful and appropriate; he refers to "issues you need to consider" (line 9) and then outlines available risk management options (lines 10-13). As the extract illustrates, information transfer is characterised by the privileging of "expert over lay knowledge and perspectives" (Gravois Lee and Garvin, 2003:451). Such a stance is demonstrated when the doctor breaks the flow of information, by making reference to:

Doctor: Other issues for me to tell you about.

Consultation with Susan, line 22.

This interruption in his information transfer functions to demonstrate that the doctor is careful to ensure that he is being seen to be acting in the patient's best interest. He is transferring his skills, knowledge and expertise so that the patient can subsequently reach an informed decision, and thus seems to be following the rules for good practice in patient-centred medicine.

However, throughout this information transfer the patient is rendered mute and is not able to follow-up upon any of this information until later in the consultation, when the doctor leaves a space for her to ask any questions. Gravois Lee and Garvin (2003) argued that in such a scenario the patient is acting passively. However, I disagree with this argument: a patient's silence can be seen as a non-verbalised action, or an unmarked acknowledgement (Heritage and Sefi, 1992). Dingwall and Robinson (1990) argued that a patients' silence being recognised as passive resistance to the utterances being made was an over-interpretation. The patient may wish to remain silent until they have gathered further information. Yet, regardless of how the patient's silence is perceived, an imbalance in the relationship exists because the doctor possesses greater levels of relevant knowledge, and decides what information to impart.

Within any information giving monologue, the material the doctor provides is that which he considers to be the most appropriate for the patient to receive. Frankel considered that, "speech produced in doctor-patient 'interviews' is far more constrained by utterance type and speaker identity than in casual conversation" (cited in West, 1983:76). Thus compared to routine casual conversation, where each party is able to introduce new topics of discussion, in the medical conversation it is the doctor who is most likely to control the content and quantity of information. Therefore, although the doctor may labour under the best intentions to fulfil his obligations under a patient-centred model of medical practice, it is doubtful whether his actions can be viewed as truly patient-centred.

Tudor Hart reasoned that for "doctors and patients to consult with optimal efficiency, they become co-producers" (1998:51). He subsequently concluded, "consultations are not units of consumption, but units of production" (1998:51). Therefore following Tudor Hart, even if the consultation is characterised by information transfer and the patient is rendered mute, the consultation should be perceived as patient-centred. The patient is listening and gathering information, and "active listening requires intense concentration" (Ford et al, 2000:554). Thus the patient is participating in the production of the interaction that develops between herself and the doctor.

A further example of patient-centred medicine can be illustrated with the accounts of their risk management decisions given by Jen, Jill and Jade. All three women declined

to have prophylactic mastectomies despite reporting that their doctors had advised them that the procedure would be the best way to reduce their risk of developing breast cancer. In observed consultations, the issue of prophylactic mastectomy was described as being:

50 Doctor: The only way to convincingly reduce the risk of developing
51 breast cancer.

Consultation with Louise, lines 50-51.

Women's decisions to decline prophylactic surgery demonstrate a variation upon Bloor and Horobin's (1975) double bind argument. Whilst discussing a more traditional setting for doctor-patient interaction than genetic counselling, Bloor and Horobin referred to the double bind to explain the conflict that can arise between the doctor and the patient. They suggested that problems could occur because patients are placed in a contradictory situation, which they termed 'the double bind'. Bloor and Horobin described the patient as "someone who is able to assess symptomatology with sufficient expertise to know <u>which</u> conditions he should present, and <u>when</u> he should present them…. but at the same time, one who, having assessed his own condition, will defer to the doctor's assessment on presentation" (1975:276; original emphasis). Whilst medical opinion considers bilateral prophylactic mastectomy to be the only effective means of reducing the risk of breast cancer (Hartmann et al, 1999), and likewise, prophylactic oophorectomy to reduce the risk of ovarian cancer, Jen, Jill and Jade chose not to undergo surgery. Their decisions placed the doctors in a double bind. The women were asking the doctor to withhold surgery and thus ignore medical opinion. This request created an inherent tension between the doctor's obligation towards his patient within a patient-centred model of medical practice, and his professional obligations. Parsons explained:

> the role of the physician centres on his responsibility for the welfare of the patient in the sense of facilitating his recovery from illness to the best of the physician's ability.

Parsons, 1951:447.

By declining surgery, women were rejecting medical opinion and choosing a less effective, uncertain prevention strategy. Such action denied the doctor the opportunity

to reduce the woman's risk, and in Parsons' terms, facilitate her recovery from illness. Nevertheless, the doctor executed the patient's decision.

iii. The collaborative model of doctor-patient interaction.

Thus far, the models of doctor-patient interaction discussed have relied upon either the doctor or the patient solely reaching a treatment decision. However, the following model argues that the doctor and the patient should participate as equals in any decision that it made. Consequently, the collaborative model of doctor-patient interaction can be recognised as an amalgamation of the approaches discussed thus far.

West (1983) argued that within the medical consultation, the provision of information should be an exchange between the parties: it should be a two-way process. The patient should have the opportunity to question the doctor, and also feel able to contribute his or her own knowledge to the ensuing conversation. Compared with the examples of information transfer discussed previously, data reflecting instances of information exchange within the consultations created a different outcome in terms of the interaction between the doctor and the patient.

In the following data extract, the doctor gives the patient the opportunity to seek further information.

39 Doctor: Do you have anything else to ask?
40 Susan: Yes, **I've made a list of things that I want to ask.**

Consultation with Susan, observation, lines 39-40.

Susan had previously met her doctor and the purpose of this consultation was to follow up upon any decisions that she had reached regarding whether to undergo genetic testing. As such, Susan's "list of things that I want to ask" (line 40) illustrates that she had prepared for the consultation. She is aware of the gaps in her knowledge that when addressed will enable her to make an informed decision. Petersen and Bunton argued, "in the context of the new genetics, the individual is conceived not as a passive recipient of expert advice, but as an <u>active</u> seeker of information and 'consumer' of health care services" (2002:6; original emphasis). Thus, Susan's action of preparing a list of

questions demonstrates that as a health care consumer she was actively seeking information.

Further examples of patient's taking or being invited to take an active role were present in the consultation data. Several times the doctor asked the patient to "tell me what you understand" (Consultation with Louise, line 11; Consultation with Jade, line 6; and, Consultation with Wendy, likes 43-44). Whilst Wendy replied stating "nothing" (line 45), both Jade and Louise were able to tell the doctor what they understood about being at-risk albeit in a limited manner. Bowles Biesecker and Marteau suggested that patients should have "an appreciation of the inheritance of a genetic condition and the integration of genetic information into a useful framework" (1999:133). Jade and Louise were able to utilise the information they had gained to form some understanding. Following his earlier question, the doctor then asked each patient "is there anything else" (Consultation with Jade, line 74) and "is there anything else that you'd like to know" (Consultation with Louise, line 61). However, both declined the opportunity to seek further information. Such utterances may illustrate how both women believed that they had received all of the information that they would require to make a decision. However, the data may also suggest that because this was their first consultation, both Jade and Louise required time to consider the information gathered from the consultation. As Susan's actions in her consultation demonstrated, any gaps in their knowledge could be addressed in subsequent meetings.

Shared decision-making (SDM) is at the crux of patient-centred medicine (Godolphin, 2003). It is complementary to the non-directive approach advocated in genetic consultations (Elwyn et al, 2001), and describes the equal involvement and participation of both the doctor and the patient in the encounter. It is thus an example of collaborative medical interaction.

Godolphin depicts SDM as the "middle ground between the 'nanny knows best' model of paternalism and the 'rampant consumerism' – an ideal that aims to reconcile professional power and the ethic of informed choice" (Godolphin, 2003:692). Within the SDM model, information exchange between the doctor and the patient is a pre-requisite (Gravois Lee and Garvin, 2003), as is agreement with the final decision (Charles et al, 1998).

As I discussed previously, genetic consultations are built around the premise that the patient ought to make the final decision, as it is the patient who has to live with the result. Therefore, it is not surprising that most of the women involved in this study reported that they had participated in the decisions regarding whether to undergo genetic testing and risk reducing prophylactic surgery. However, because of the research design employed, it is impossible to assess whether these decisions were truly reached in an egalitarian, shared environment as portrayed by Charles et al (1998).

Moreover, whilst both parties may collaborate and work towards a mutual goal, the relationship between the doctor and the patient continues to be built upon foundations of knowledge and status imbalances. As with both the disease and patient centred models of doctor-patient interaction, the doctor has the ability to influence the patients' decisions by controlling the content and amount of the information that he passes on. Yet, an imbalance exists, for it is the patient, not the doctor, who is at-risk and facing the uncertainty related to carrying a positive BRCA gene. Therefore, although the doctor and the patient can work together within the consultation, it is unlikely that the ensuing doctor-patient relationship will be truly egalitarian. Consequently, like Godolphin (2003), I propose that such a model of medical practice is an ideal type, and as such, is unlikely to be attainable in practice. Edwards et al argued:

> in the reality of ordinary health care practices, away from these ivory towers (academic institutions, consumer representatives and advocate organisations), shared decision-making remains a relative rarity or at best, a novelty whose place is uncertain.
>
> Edwards et al, 2003:33.

Whilst Edwards et al describe SDM as "a relative rarity or at best, a novelty" (2003:33), I would argue that this is an over generous statement. SDM, together with the notion of an egalitarian doctor-patient relationship, can be nothing more than a utopian fantasy. As long as the patient is in a vulnerable position (Parsons, 1951), in which they are placed because they have sought medical intervention, the interaction produced will be unbalanced. The rejection of a shared model of decision-making and an egalitarian doctor-patient relationship does not however mean that the collaborative model of doctor-patient interaction is also dismissed.

Given the data discussed thus far in the chapter, it seems appropriate to consider that the interaction both observed and recalled in the accounts provided by the women during the interviews, depicts a collaboratively produced doctor-patient relationship. Tudor Hart (1999) argued that each recipient should be recognised as a co-producer of the consultation. However, during the interviews, women spoke about their desire for personalised, individualised and holistic care, and the relative success and failure of the doctors to react to this. Such a requirement has been ignored in many of the existing mainstream models of doctor-patient interaction, which is surprising, considering the sensitive nature of breast cancer.

Feminist medical sociologists have drawn attention to the need for doctor-patient interaction to be collaboratively produced so that the individual needs of each woman can be heeded. For example, importance has been given to 'woman-centred' approaches to medical interaction (Reigar, 2000). Much of this work has derived from feminist studies of childbirth, in which "expanding women's rights and choices" about their medical treatment is encouraged (Reigar, 2000:2). As I discussed in chapter two, feminist medical sociologists have been critical of the medicalisation of the birthing experience, and have called for women to give birth 'naturally', without medical intervention. Essential to woman-centred or 'gynocentric' care (Davis-Floyd, 1998) is the notion that women's individual needs must be respected. In terms of maternity care, this may mean, as Fahy and Smith (1999) reported, that women want a highly technical, medicalised birthing experience, despite this sometimes clashing with the aims of midwives and obstetricians. Thus, the key import for woman-centred care is for women to be able to receive the 'custom-made experience' (Reigar, 2000:9) that is right for her at that time, and for her concerns about the medical experience to be addressed.

Brown et al argued that, "the relationships between the patient and her doctors throughout her experience with breast cancer are fundamental in the process of coming to terms with her illness and learning to live with cancer" (1999:127). An essential component of this interaction is that the doctor should be aware that "sensitivity and responsiveness to the patient's feelings of vulnerability are important" (Brown et al, 1999:127).

Many of the women reported that they had wanted to feel comfortable and at ease in the presence of the doctors. Whilst Jen described the affability of her doctor, depicting him as "great, genuine and approachable" (Jen, interview, lines 159), Trisha recalled how the same doctor made her feel:

392 Trisha: When I first met him, I felt very
393 comfortable with him and I think that is part of it as well. If you
394 feel comfortable with it all, it does make it easier, and makes
395 it happen easier.

Trisha, interview, lines 392-395.

As the extract demonstrates, Trisha structured her account in such a manner so that her perception of the relationship she experienced with her doctor enabled her to come to terms with being at-risk more easily than might have otherwise been is illustrated. Another feature which Trisha felt was a positive contribution to her relationship with the doctor was his ability of making her feel like a person, rather than an object of medical enquiry. She described:

273 Trisha: I felt that it was dealt with very humanely, very personally. I
274 felt like I have been dealt with as a person, not a number, not a
275 statistic, not, umm, how can I say it, a research item – would
276 that be the right word, I don't know? But I feel that I have been
277 dealt with as a person and as an individual even though it is a
278 family thing.

Trisha, interview, lines 273-278.

Trisha's account of her relationship with the doctor relies on her reporting that she felt that the doctor treated her "humanely, very personally" (line 273) and "not [like] a statistic" (line 274). For Trisha, the individualised and 'person-centred' care that she received was a positive aspect of her at-risk experience. Like Trisha, Zoë reported that the relationship with her doctor benefited as she felt as if she were treated like a person opposed to a patient at-risk of a disease. However, unlike Trisha, whose relationship with her doctor was still medically orientated, Zoë considered that she and her doctor had a relationship akin to a friendship. She described how:

560 Zoë I feel the way you do when you see your friends, you know,
561 Doctor C and Nurse H, I don't look at them as doctor and nurse
562 you know.

Zoë, interview, lines 560-562.

Zoë reported that she perceived her relationship with the doctor and the nurse to have developed into a friendship. She made a distinction between the bond that she considered had developed between them, to that of a 'normal' doctor-patient, or nurse-patient relationship. However, implicit within this account is the notion that Zoë feels comfortable and at-ease about the relationship that she experienced.

Trisha's comment that she felt that the doctor treated her "humanely, very personally" (line 273), "not [like] a statistic" (line 274), and Zoë's perception that the doctor and the nurse were her friends (line 560) clashes with the accounts that other women gave regarding their perceptions of the doctor-patient relationship they experienced. Louise mentioned that the extended delay she had experienced in waiting for an appointment to see a consultant made her feel like another person on a long waiting list, opposed to an individual who was at-risk. She explained:

478 Louise: Umm it, you felt it was personal when you saw them but the
489 whole process of having to wait to see the consultant and you
480 know, that wasn't, you just felt that you were another one on the
481 list.

Louise, interview, lines 478-481.

Although Louise reported that she found the consultation to be "personal" (line 478), the experience of waiting for an appointment detracted from the overall image of the personalised care that she had received. Rather than being a woman facing a risk of HBOC, Louise perceived that she was just one of a number of women on a waiting list (lines 480-481). A further example of women reporting that the doctor failed to recognise them as a person but as a disease can be seen with Zoë's explanation of her treatment by a doctor when she noticed a change in one of her breast implants.

Earlier in her interview, Zoë had spoken in positive terms about her relationship with her surgeon. However, her account altered when she recalled a consultation performed

by a different doctor. Zoë's relationship towards the second doctor stood in direct contrast to that which had with her surgeon. Whilst she was accustomed to a consensual relationship with her surgeon, when she visited the second doctor to investigate why one of her breast implants had shrunk, she experienced a different type of doctor-patient relationship. Consequently, Zoë stated:

457 Zoë: Well, I nearly ended up arguing with him, with Doctor F
458 Emma: [identifying utterance omitted]
459 Zoë: Err, yeah. He was just fobbing me off, telling me anything and
460 everything and I thought, you don't fob me off.

470 Zoë: I'm just a number to him [Doctor F], whereas Doctor C, **perhaps I**
471 **am just another number to Doctor C**.

Zoë, interview, lines 457-460 and 470-471; original emphasis.

Zoë considered that because they had not had any previous contact, the second doctor did not understand her anxiety regarding the change in the size of her breast implant. She explained, "he was just fobbing me of, telling me anything and everything" (lines 459-460). Zoë reflected that because Doctor F only knew her as a patient, opposed to a person, he was unable to understand her anxiety caused by the change in appearance of her breast implant. The experience led Zoë to question her existing relationship with her surgeon, Doctor C. She appeared to realise that whilst she might consider her doctor to be a friend, it was possible that for him, she was just another patient (lines 470-471). Jill spoke about how her relationship with the doctors made her feel like a statistic. She also described how she felt as if they had treated her like a guinea pig. She recalled:

342 Jill: I just think, is that it then,
343 am I another statistic, because as I've said before, when I've
344 been to genes thing, I feel like a guinea pig, **I do feel that I am** a
345 statistic to them and not a human being, they don't know my
346 life and they don't know me and at the end of the day, they will
347 go home and I'll go home and that's it, you know what I mean,
348 there is no, there's no real connection there and I feel that its
349 all trials, it's just a trial and I'll be a number.

Jill, interview, lines 342-349; original emphasis.

Jill's account relies on her sensing that there was no personal connection between herself and the clinical team. She commented, "they don't know my life and they don't

know me and at the end of the day, they will go home and I'll go home and that's it" (lines 345-7). This lack of connection was used to emphasise Jill's belief that she was only a number and not a person to the clinical team. Moreover, her account also points to the uncertainty involved in a new medical technology. Jill reported that she felt as if she were a "guinea pig" (line 344) participating in a clinical trial (line 349).

The perception that she was just a number and treated like a guinea pig influenced another of Jill's accounts. Jill rationalised that her discharge from the Department of Gynaecology demonstrated that the doctors had treated the disease rather than the person. She felt that the doctors had done their job and had now decided that they did not need any further contact with her, as following her hysterectomy her risk of ovarian cancer had been managed. However, Jill still had related issues that she thought the clinical team could address. She explained:

614 Jill: I don't see Doctor B anymore, nobody asks me about that
615 and I'm left, left for it to take its course now. Like I say, I'm a
616 statistic now, that's it, we've done it, bye, thank you, it's a bit like
617 that, and that makes you feel on your own.

Jill, interview, lines 614-617.

Jill's account demonstrates the conflict that exists between disease and patient (or woman)-centred models of medical care. Now that her risk of ovarian cancer had been addressed, Jill had been discharged from the care of the clinical team. However, because of this, she considered that she was on her own, describing, "that's it, we've done it, bye, thank you" (line 616). Consequently, Jill believed that her risk was now left to take its course and would no longer be monitored. Jill's reported distress suggests that wanted a more long-term approach to her risk-management. Yet from the medical point of view it is acceptable to discharge these women from the hospital. However, the women appeared to want to remain as hospital patients, drawing reassurance from this

Like Jill, other women talked about the novel status of genetic testing and risk-reducing surgery; such is the level of innovation, women felt as if they were guinea pigs with the risk-reducing procedures and the efficacy of treatment being tested on them. Zoë reported that she found the experience of being a guinea pig to be positive. Her

perception was based upon the grounds that her surgeon had learnt from carrying out her operation. She explained:

228 Zoë [the doctor] was itching to get in there (laughs), yeah,
229 get in there, 'let me get it done and then I know what I am
230 doing'.

Zoë, interview, lines 228-230.

During the interview, she explained that her surgery was the first time that the surgeon had performed the operation. Thus, central to Zoë's perception that she was treated like a guinea pig is the fact that she was the first woman to test BRCA positive and choose to undergo risk-reducing surgery at Hospital X. Therefore, justifying her treatment and the surgeon's lack of previous experience, she stated:

724 Zoë I was the first one, so basically whatever
725 I've said, they've learnt and carried on to other women.

Zoë, interview, lines 724-725.

The above extract illustrates elements of altruism or selflessness on Zoë's behalf. She recalled, "whatever I've said, they've learnt and carried on to other women" (lines 724-725). During the course of the interview, Zoë mentioned negative experiences related to her hospital care, including coming round from the anaesthetic to discover that she was flat-chested, and the negative emotional and psychological impact of this. However, she argued that she would not have wanted any of her experience to change. Zoë felt that the problems that she had encountered had enabled the surgeons to learn and this had consequently benefited other women who had genetic testing and risk-reducing surgery following her.

Joanna used the term 'guinea pig' to explain the extra attention that staff members paid her once they became aware that her aunt carried a positive BRCA mutation. She compared this attention to the lesser level of intervention she received prior to this and recalled:

389 Joanna: Obviously I am now an extremely interesting guinea pig for
390 Them, and they are dying to do a genetic test on me, its
391 obvious, erm, so its reassuring in a way that suddenly I am
392 more interesting, and therefore perhaps I'll be looked after.

Joanna, interview, lines 389-392.

Joanna found the extra attention to be "reassuring" (line 391) and postulated that the greater interest in her would lead to greater levels of care, commenting, "perhaps I'll be looked after" (line 392). However, the account demonstrates that Joanna has failed to appreciate whom testing would benefit. Her explanation seems to suggest that should she have genetic testing, it would be the hospital, rather than herself or her family, who would benefit.

Whilst some women found that being treated like a guinea pig was a positive experience, others described negative experiences. Jill found the experience traumatic, describing her fear, anxiety and intimidation. She stated:

76 Jill: When I first went in I think
77 what frightened me with the surgeon and he said 'oh can I have
78 all these students in' and I said 'oh yes', the there were these
79 three or four students and then I had, I think three doctors in
80 and I just had to whip off my bra and sit there.

Jill, interview, lines 76-80.

A central theme within Jill's account is her intimidation. Firstly, she reported that she felt intimidated by the surgeon asking if a group of medical students could observe her consultation (lines 77-78). Secondly, Jill explained that her anxiety increased because "she had to whip off [her] bra and sit there" (line 80).

Many patients might find being examined by a group of doctors to be intimidating. Jill reported that the anxiety she felt was intensified because she had not expected to remove her bra in front of such a large group of strangers. As the following quotation demonstrates, Jill found it difficult to accept a consultation style that objectified her breasts and neglected to acknowledge her as a person. She explained:

355 Jill: You go in and it's just a medical and it's just
356 the way they looked at me the first time and they were all there
357 and felt like, I was going to say a lump of meat, but just not a
358 person, they desensitised me to, to me, you know that I mean,
359 they didn't, it's like they weren't really talking to me, and they
360 were talking to each other and just going on about my breasts
361 and discussing you and if we do this and do that and I'm just
362 wanting to say hang on a minute, this is me you're talking
363 about, and you can discuss it with me first.

Jill, interview, lines 355-363.

Jill's explanation refers to how she was made to feel like a "lump of meat" (line 357). Her account demonstrates a further example of how doctors treat the disease rather than acknowledging the person. Jill described how the doctors were "desensitised" to her as a person (line 358). She reported that they ignored her throughout the consultation and discussed her breasts as if they were objects, rather than part of her body. However, it could be postulated that the doctors' actions in distancing themselves from the patient were influenced by the 'private' and sensuous nature of the body part that they were examining.

Discussing a gynaecological examination, Emerson (1970) argued that medicine takes a matter of fact standpoint. Similarly, Freidson described how "the practitioner, looking from his professional vantage point, preserves his detachment by seeing the patient as a case to which he applies the general rules and categories learned during his protracted professional training" (1975:286). During the medical consultation, the meaning ascribed to the patient's body part alters. For example, no longer does the breast symbolise a woman's femininity; rather, it is an object for examination. Pilnick and Hindmarsh (1999) described how "the body is parcelled into regions", and the patient's body is "visually reduced to its relevant parts". Stewart and Brown explained:

> through the separation of subject and object, complex phenomena [can] be reduced to their simplest components…..as the medical model became more abstract and focused, it also became dramatically removed from the experience of the patient. The focus was on diagnosis with an emphasis on physical pathology. The method was analytical and impersonal.

Stewart and Brown, 2001:98.

Emerson rationalised that doctor's depersonalise and desexualise the medical examination in order that, "no one is embarrassed and no one is thinking in sexual terms" (1970:78). Rather, the doctor's "nonchalant pose attempts to put the gynaecological examination in the same light as an internal examination of the ear" (Emerson, 1970:78). Because the consultation had ignored the person and focused only on the at-risk body part, Jill reported that she felt alienated. Disease-centred medicine objectified her breasts, and ignored her. Similarly, Edelman found that the medical perspective clashed with women's own experience as, "mammograms isolate the breast in examination, de-emphasise its relationship to the whole body as maternal or sexual, and view the breast instead as a disembodied female part which, if flawed, may be removed or rebuilt" (1994:25).

6.3. An exceptional doctor-patient relationship?

Szasz and Hollender (1956) considered that no one model of doctor-patient interaction could prevail in all situations, and the data discussed in this chapter has reflected this. However, given the support that Szasz and Hollender's seminal paper both has had and continues to have nearly 50 years following its publication, it is paradoxical that research consistently points to the use of the shared decision-making model as the optimal requirement for modern day, patient-centred medical practice.

Pragmatically, it remains that, "even when doctors fully inform patients, know their preferences and share decision-making, the balance of power lends its favour to the doctor" (Goodyear-Smith and Buetow, 2001:450). In this chapter I have discussed several types of medical interaction, and reached the conclusion that regardless of the model enacted, the doctor still has the greatest influence in determining the style of consultation evoked and the issues addressed within it.

In analysing women's accounts of the doctor-patient relationship, I have shown that "physicians did not view medical encounters as a chance to exchange information, [or] engage in a dialogue to understand the needs of the 'whole' patient" (Gravois Lee and Garvin, 2003:454). Rather, the accounts given by the women illustrated that many of their needs were unmet by the doctors. Brown et al suggested that, "the right type and amount of information, tailored to that patient" is crucial (1999:127). It is postulated

that the pressures in meeting service demand mean that the needs and agendas of patients can be overlooked.

However, it is accepted that the needs of patients may not simply be being overlooked. Rather, they may be diametrically opposed to the needs of the medical profession. For example, earlier in the chapter I discussed Jill's dismay whilst recounting her experience of having a breast examination carried out in front of a group of medical students. Jill reported that she found the objectification of her breasts to be a negative experience, yet for the medical team, the objectification of her breasts was essential. Jill reported that she wanted to receive personalised care and not feel like "a lump of meat" (line 357), yet her need could not be met. Heath commented, "the doctor has specifically to examine parts of the body whilst retaining some detachment" (1986:101); such detachment was possible because:

> the obligations and responsibilities typically associated with face-to-face interaction are suspended and replaced by a framework of participation which provides for the smooth running of the physical activity, a framework in which doctor and patient appear to be disengaged from each other's actions.
>
> Heath, 1986:102.

By disengaging from Jill's breasts as anything other than objects for medical examination, in Heath's opinion, the doctor facilitated "the smooth running of the physical activity" (1986:102). Had the doctor not objectified Jill's breasts, his actions would have been considered as inappropriate and he may have faced disciplinary action. Consequently, some patient needs cannot be met.

Parsons (1951) suggested future models of the doctor-patient relationship should allow the interaction occurring between parties to be illustrated. A commitment to this would allow us to understand how the doctor-patient encounter is co-constructed or co-produced by those involved in it. Moreover, it would allow the needs of each individual party to be given an opportunity to be addressed, as advocated by the 'gynocentric' care recommended by feminist writers studying the birthing experience. Therefore, I propose that a more sophisticated understanding of doctor-patient-interaction is required to address the needs of both the doctor and the patient in contemporary medical care.

Edwards and Elwyn (2001) proposal of "dialogue centred care" where "shared responsibilities for the care process between patients and professionals, and mutual rights and obligations" exist and "can differ [according to each] patient and problem" may be a solution (Edwards and Elwyn, 2001:xvii).

The need to re-conceptualise the doctor-patient relationship as it currently stands, and therefore move away from the three static models of interaction illustrated in figure 17, is necessary in order to examine contemporary health care practice in all realms of medical enquiry in which patient participation is sought. The difficulty in defining an optimal model to describe the doctor-patient relationship is not therefore unique to genetics. Support for the genetic exceptionalism thesis is not given.

The changing demands made by patients have altered the doctor-patient relationship from its original conception of the obligations inherent in the doctor role and the patient role (Parsons, 1951). Young considered:

> as the era of patients' rights has progressed, where the obligation of the physician to provide information becomes a legal, as well as an ethical standard, the patients' power to determine and direct care pushes the relationship to a more equitable and equal power relationship. We approach a more contractual view of medicine, despite the uncertainty of the outcomes. The patient, often with less than complete information, weighs the risks and benefits of proposed care and plots a course of action in a sort of consultation with the physician. Physicians become more accountable for communication and provision of knowledge to the patient.
>
> Young, 2004:7.

Young's quotation suggests that contemporary medical practice is characterised by the provision and communication of information, which in turn, enables the patient to make an informed decision. In this sense, genetic medicine, whilst providing an uncertain arena in which the doctor-patient relationship is situated, provides nothing unique or exceptional compared to other examples of medical practice. Patients are seeking greater levels of information, sharing their opinions and demanding holistic, person-centred care across the medical spectrum (Michie et al, 2003; Van Dulmen 2003). Consequently, in concluding this chapter I propose that there is nothing exceptional about the doctor-patient relationship when the consultation investigates genetic risk.

However, the existing models of doctor-patient interaction are outdated and require re-examined in order that they can adequately account for 21st century medical interaction.

In this chapter I have shown that patients are demanding 'person-centred care'. This necessitates the doctor "attending to the patient's experience and values as well as exploring with them the degree to which they prefer to be involved in the management decisions" (Stewart and Brown, 2001:99). In turn, this will lead "the patient of the future [to] be less deferential, more aware of the risks inherent in medical treatments and more choosy. They will have higher expectations and a greater desire to participate actively in decisions that affect them" (Coulter, 2001:313). Whilst not all patients will want to act autonomously from the doctor, as Trisha and Joanna's deference illustrated, the medical profession should be more alert to the diverse needs and concerns of each individual patient. In this chapter, I have argued that whilst doctors appear to be alert to the theoretical requirement that they are responsible for providing patients with information, in practice, they appear to be less responsive to, or aware of patients' wider concerns.

Having characterised the dominant models of medical interaction and decision-making within contemporary medical practice, the next two data chapters investigate the decisions that women were asked to make upon their referral to the Family History Clinic.

Chapter Seven. Genetic Testing Decisions.

> You know that the decision will affect the rest of your life, one way or another, and you have to be ready to do that.
>
> Laura [28].

Upon referral to the Family History Clinic, women were faced with the decision whether or not to undergo genetic testing. This chapter discusses the rationales and justifications given for this decision. In this chapter, I examine whether the decisions and the justifications for these decisions are unique to carrying a mutated gene, therefore enabling them to be seen as an example of genetic exceptionalism.

7.1. Unexceptional accounts?

In chapter four I argued that the stories told by the women whilst being interviewed should be treated as accounts, constructed by participants to direct the manner in which they and their actions are represented. The arguments made in this chapter illustrate that in constructing their accounts, the women participating in this study wished that the interviewer, the analyst and the reader might perceive that the decisions they took were moral, responsible and fitting for what our society considers to be a good citizen. Murphy (1999; 2000; 2003) reported similar influences upon the accounts that women gave regarding their decision to bottle or breast-feed newborn babies. Taking a similar stance to Goffman (1959), Murphy discussed women's moral accounting and argued, "rhetorical construction of moral meaning through talk is a crucial element of self-protection" (2000:303; emphasis added).

In relation to this thesis, the key to understanding women's accounts of their genetic decision-making is the notion that the women are seeking to avoid the blame for any negative implications associated with being at-risk, or any negative consequences of the decisions that they might subsequently make. Goffman (1959) considered that the essence of self-presentation was self-protection. Thus, it is likely that women's accounts

[28] Quotation from interview with Laura.

are constructed so that any negative implications of their decisions can be nullified (Orbuch, 1997).

Miller (1976, cited in Hallowell, 1999) explained that a great part of woman's identity has been portrayed in relation to her capacity to care for and nurture others, regardless of any negative impact that this might have upon her own personal health. Murphy (2003) referred to such an obligation as an example of biologico-moral responsibility. Much of the data discussed in this chapter, derived from both the interviews and the consultations that were observed, demonstrates that parenthood influenced women's decisions to find out whether they were genetically predisposed towards HBOC. Therefore, women's actions were influenced by their biologico-moral responsibility.

During a consultation at the Department of Clinical Genetics, Linda justified her attendance to the doctor (and the observer?) in relation to wanting to know about her own level of genetic risk[29]. However, she extended her justification, drawing upon the risk that her daughter might have inherited. Linda explained that the information that she hoped she would gain from the consultation would not only enable herself to be informed and make choices, but would also allow her 14 year-old daughter to be able to do so as well[30]. Similarly, Julie reasoned that one of the main factors for seeking a referral to the Family History Clinic and undergoing genetic testing, was because she planned to start a family and wanted to be aware of any mutation that her child could potentially inherit. The presence, or the likelihood of having children in the near future compelled women to discover if they carried a mutated BRCA gene. For example, when I asked Louise about her decision to have genetic testing, she explained:

26	Louise:	I thought about it a lot anyway, but then, when it actually
27		came to it, I thought, do I want the test or don't I, but **I've got**
28		**a five year old daughter, so there was never any doubt.**

Louise, interview, lines 26-28; emphasis added.

Although Louise knew that she had a family history of breast cancer, when she was offered testing and was required to make the decision as to whether to accept it, she was uncertain about what action to take. She started to question whether she should have

[29] As discussed in chapter five, it was her mother, not Linda who had been referred to the Clinic.
[30] See chapter six for an in-depth discussion.

testing, describing how, "when it actually came to it, I thought, do I want the test or don't I?" (lines 26-27). However, when justifying her decision to undergo genetic testing, Louise ignores her earlier indecision, and stated that, "there was never any doubt" (line 28). Her account illustrates that the motivation for her apparent shift from questioning whether to have genetic testing to then being certain that she would have the test, was her responsibility to her five year old daughter.

Two striking points arise from Louise's account. Firstly, for whom did she make the decision to undergo genetic testing? Her account is constructed so that the identity of the beneficiary is ambiguous. On one hand, it appears that her decision to have testing is totally altruistic and that the outcome, regardless of the result, will only benefit her daughter. However, although Louise perceives her daughter to be the primary beneficiary of testing, she would not be the sole beneficiary. Whilst it is likely that the child would benefit indirectly from the resolution of her mother's risk, it is the mother herself who would receive the greatest immediate benefit. By undergoing testing, Louise would (and consequently did) resolve her anxieties about being at-risk of developing HBOC[31].

Secondly, what is the relevance of the child's age in Louise's justification of her decision? Both Louise and Linda spoke about how having young children prompted their decision to investigate their genetic risk, and thus echoed Murphy's (2003) argument about biologico-moral responsibility. Both women referred to the ages of their daughters, without being prompted to do so. Louise's daughter was five years old, whilst Linda's daughter was 14 years old. Although discussing the rise of surveillance medicine, Armstrong (1995) described childhood as a vulnerable period. He argued that this justified greater levels of medical attention and protection. In justifying their decisions to have genetic testing as a means of protecting the young and seemingly defenceless, women may be constructing the perception that their children are the innocent victims of inherited risk.

The responsibility of being recognised to be a good mother also influenced women's accounts of their decision-making to have risk-reducing surgery, which I address in

[31] When Louise underwent genetic testing, no BRCA mutation was found.

chapter eight. Murphy reported that, "a 'good mother' is considered to be "one who maximises physical and psychological outcomes for her child, regardless of the personal cost" (2000:292). Thus, it is possible that in addition to their own desire or need to reduce their risk of developing HBOC, some women might construct their account of their decision-making to illustrate that the choice to have surgery was indeed influenced by their moral responsibility to "maximise physical and psychological outcomes for [the] child, regardless of the personal cost" (Murphy, 2000:292). Moreover, women may feel guilty about subjecting their children to danger, when a fundamental moral role of a parent is that of a protector. By undergoing surgery, women are protecting their children from what could be termed the worse possible scenario, namely watching their mother potentially develop and die from cancer. Forna (1999) commented:

> women feel guilty because they are made to. Mothers are told that every failure, every neglected task, every dereliction of their growing duties, every refusal to sacrifice will be seared upon the child's psyche, will mar his or her future, and damage not only the mother-child relationship but every subsequent relationship in the child's life.
>
> Forna, 1999:12.

Forna's argument suggests that women are made to feel guilty if they fail to protect their child from harm. Similarly, Hopwood proposed:

> The theory of parent/child attachment is interesting….because it suggests that disruption to this relationship because of separation, illness or death can have an influence on relationships and behaviour in adult life.
>
> Hopwood, 2000: 389.

Consequently, women are compelled to act in a responsible manner in order to protect their children from any harm. In relation to being at-risk of HBOC, both Forna's and Hopwood's argument would seem to indicate that women might feel obliged to undergo genetic testing in order to shield their child from risk.

Jill rationalised her decision to undergo genetic testing and a prophylactic hysterectomy in terms of her perception that she had a responsibility to be there for her children, and prevent them from watching her become ill. She recalled how she herself had watched her own mother's progressive decline in health:

711 Jill: **I don't want my daughter to**
712 **see me like I saw my mum** because I think **it was a very slow,**
713 **drawn out death** and cancer in particular can be a really
714 horrible death and to see somebody in, deteriorate so, **it takes**
715 **a lot to overcome those scenes and times and remember the**
716 **healthy looking, and I don't want my children to see me**
717 **looking like that.**

Jill, interview, lines 711-717; emphasis added.

Jill's account emphasises that she took the decision to undergo testing and have surgery because she wanted to protect her daughter from watching her become unwell. Moreover, by continuing her justification, stressing that death from cancer can be "very slow and drawn out" (lines 712-713), Jill implies that she suffered from watching her mother's decline and subsequent death. A similar argument is made by Hallowell (1999), who argued that women were influenced by their mother's suffering. She explained:

> [women] were still haunted by their feelings of helplessness they experienced as they watched the suffering of their mother…..in the terminal stages of cancer, and perceived themselves as having a responsibility to do whatever was necessary to protect their relatives from such an emotional ordeal.

Hallowell, 1999:111.

Jill's account mirrors Forna's (1999) suggestion that any negative event in a child's life will firstly be blamed upon the mother, and secondly, will affect the child's psyche and future. Jill's explanation also echoes Hallowell's argument that women should protect their relatives from "emotional ordeal[s]" (1999:111). By asserting that she "didn't want [her] children to see [her] looking like that" (lines 716-717), Jill is providing both clarification for her decision to have surgery, and defending herself from any claim of 'deviancy' that she had not done all she could to protect her children by not having a prophylactic mastectomy.

Trisha claimed that her decision to have surgery was shaped by the presence of the younger females in the family. She recalled:

Trisha: **One of my reasons for, or my main reason** I should say of going down the surgery route is you know, **the next four girls could be facing this decision and I would like them to look at me and think well Auntie Trisha had it done in her 40s, you know, she still wears her strappy tops on the beach, still goes and lives a normal life and it doesn't bother her very much and I want to give them a good picture to look at**, I would like to think that they could look at me and think, you know, it is a big deal, but for them to sort of take it on the chin and not be devastated. I can give them a better picture then, or hope or get something positive than its all, **it's part and parcel of being a Mum I think.**

Trisha, interview, lines 258-270; emphasis added.

Trisha's account of her surgical decision-making is interesting for many reasons. Firstly, in her opening utterance she immediately engages in repair work. Although opening her explanation with the statement, "one of my reasons for" (lines 258-259) Trisha changes her justification to "or my main reason I should say of going down the surgery route" (lines 259-260), so that the influence of the four younger girls (her daughter and three nieces) plays a larger role than it might have done if she had stuck to her initial, stalled account. In doing this, Trisha is attempting to construct the explanation that she chose to have surgery so that the girls' experience of cancer would not only be the diagnosis and treatment of her sister Laura (their mother or aunt). Rather, she wanted it to be recognised that she chose to have surgery so that the girls would see that even though she had had a mastectomy, she still looked normal[32]. Moreover, her account demonstrates that she also wanted the children to realise that although testing positive and having surgery was "a big deal" she hoped that they would "take it on the chin and not be devastated" (lines 267-268). Trisha explained her actions were "part and parcel of being a Mum" (lines 269-270). Consequently she was obligated to undergo genetic testing (and risk-reducing surgery) to ensure that the children were prepared for any challenges they may have to face later in life.

This section of the chapter has demonstrated that women's perceptions of the duties inherent in being a mother, to protect and be there for their children, were at the forefront of the accounts given to justify their decision-making. The manner in which

[32] The desire for women to appear aesthetically normal following prophylactic surgery is addressed in chapter eight.

women justified their decisions in relation to their children is not itself surprising. Rather, it would have been unexpected if the women had not mentioned their children. However, there is a need for women to be seen to be doing the 'right' thing and achieving socially accepted norms. Therefore, although being required to make the decision to undergo medical tests when you are asymptomatic might be considered to be exceptional, the justifications women reported for the decisions reached cannot be considered genetically exceptional or even exceptional, as they are indistinguishable from the justifications that women are reported to have given whilst explaining their decision to either breast or bottle feed (Murphy, 1998, 2000, 2003).

7.3. The genetic testing decision.

It is unknown whether or not four of the women participating in the research, decided to undergo genetic testing[33]. Of the remaining 12 women in the sample, 11 underwent genetic testing to discover if they carried a mutated gene that could signify a predisposition towards HBOC. One woman decided not to undergo testing. The rationales given for declining genetic testing are addressed first.

i. Declining genetic testing.

Joanna was already a Family History Clinic patient, having been referred by her GP following her request for a mammogram whilst in her early 40s[34]. She explained that she had requested mammography screening because she was worried about her family history. Nevertheless, it was not until her aunt tested BRCA positive and Joanna herself informed the hospital of this that she was offered genetic testing. However, after considering the offer, Joanna decided that, "there didn't seem to be many advantages and there seemed to be a lot of disadvantages" related to undergoing genetic testing (lines 124-5). When I asked her to elaborate upon her decision not to be tested, Joanna explained that she had "listened to the pros and the cons" (line 129), then gave two

[33] Access to May, Linda, Susan and Wendy was limited for reasons related to the conditions imposed by access to the clinical site. It was only possible therefore to observe their consultations and on that basis, the four women were not invited to participate in the interview phase of the study.
[34] Standard NHS mammography screening starts at 50 years old for women in the UK. It is suggested that the likelihood of an abnormality being picked up by mammography alone before this age, in the majority of the population, is minimal (Lucassen et al, 2001).

rationales for why she had reached her decision. Firstly, she questioned the efficacy of current risk-reducing surgical procedures:

131 Joanna: If you did have the gene, erm, there wasn't much more that
132 they could offer you positively other than to take, give you a
133 double mastectomy, but even then, I don't believe that it is
134 supposed to be 100%. **I think a double mastectomy does**
135 **reduce the risk, but it is not 100% certain.**

Joanna, interview, lines 131-135; emphasis added.

Joanna defended her decision not to have genetic testing by attacking the efficacy rate of 'preventative' surgery, arguing, "it is not 100% certain" (line 135). During the interview, Joanna reasoned that although she declined genetic testing she was still receiving the same level of monitoring that she would have received if she tested BRCA positive. However, she was eager to compare her decision with those made by the other women in my sample. For example, she asked me what decisions they had made, and what reasons they gave for them. By questioning me about the choices other women had made, Joanna sought to compare her decision with theirs, and in doing so, was investigating whether her decision might be considered deviant. Upon discovering that she was the only woman whom I had talked to who had decided not to have genetic testing, Joanna continued the defence of her decision, by emphasising that the doctors told her that there was "not much more that they could do for [her]", other than continue with the same monitoring she was already receiving (lines 185-186):

184 Joanna: I was being told that I was having the [same] monitoring as I
185 would have if I had the information, there was not much more
186 that they could do for me other than a double mastectomy
187 **which I think is terribly drastic. And at the end of the day,**
188 **it's not 100% foolproof. It does reduce the risk doesn't it,**
189 **but it's not 100% so you've disfigured yourself and got a**
190 **scar, or scars on your chest for the rest of your life, umm,**
191 **which I think is pretty horrendous really**, considering that
192 breast cancer anyway can be picked up reasonably easy.

Joanna, interview, lines 184-192; emphasis added.

This data extract illustrates Joanna's attempt to construct her decision not to have testing as being shaped by the doctor's suggestion that there was little (other than the existing monitoring) that they would offer her. Together, the two data extracts

demonstrate the extent to which Joanna's decision not to undergo genetic testing was influenced by her own beliefs regarding the available risk management options. The uncertainty associated with current risk-reducing procedures was fundamental in shaping her opinion. Joanna commented, "at the end of the day, it's not 100% foolproof" (lines 187-188), and by the end of these two data extracts, has made a similar statement a total of four times (lines 134, 135, 188 and 189). Joanna constructed her talk so that her recurring statement becomes highly obvious; the outcome of which is that the recipient of the talk focuses upon the uncertainty associated with risk-reducing surgery, and thus possibly lends support to Joanna's defence.

The efficacy of risk-reducing measures is widely addressed in the literature (for example: Hartmann et al, 1999; Meijers-Heijboer et al, 2001; Stefanek et al, 2001; Rebbeck, 2002). However, Joanna was the only woman participating in this research who explicitly addressed the uncertainty related to the effectiveness of the current risk-reducing management options. Hartmann et al (1999) reported that the efficacy rate for preventing future or further breast cancer is approximately 90%, and Morrow and Gradishar (2002) gave risk reduction estimates of between 90% and 94%. As I discussed in chapter one, the efficacy of prophylactic mastectomy is not 100%; depending upon the procedure performed, up to 10% of breast tissue remains. Consequently, women opting for bilateral prophylactic mastectomy continue to live with the threat of breast cancer, despite taking measures to reduce their risk of HBOC.

For Joanna, the prospect of undergoing major surgery only to be left with a real possibility that cancer might develop, was not an option that she was willing to choose. Moreover, as shown at the end of the last quotation, Joanna perceived that it was "reasonably easy" (line 192) to diagnose breast cancer. As a result, she considered that the treatment options available did not offer a strong enough guarantee to outweigh what she perceived to be the negative implications of genetic testing.

Joanna appeared to feel that she needed to comprehensively defend her decision not to have genetic testing. Accordingly, she continued her rationale for declining genetic testing in relation to the impact that surgery would have upon her body. Joanna stated, "you've disfigured yourself and got a scar, or scars on your chest for the rest of your life, umm which I think is pretty horrendous really" (lines 189-191). Hallowell et al

(2001) raised a similar point to that made by Joanna, regarding the difficulty of balancing the uncertain efficacy of the treatment against the disfiguring scars that a mastectomy would create. One of Hallowell et al's participants observed:

> it's sort of – I don't know, cutting your arm off for a scratch on your finger….even if they identify me as having the gene, they say you may or may not get cancer from it. You may still not get cancer from it all your life. I just think it just seems – to cut out healthy organs as a preventative measure seems drastic, unless you've got one hell of a case for doing that.
>
> Carol, cited in Hallowell et al, 2001:685.

Like Joanna, whose account emphasised the potential for disfigurement and the real possibility that cancer may still develop, Carol, Hallowell et al's respondent, also questioned the efficacy of prophylactic surgery. She considered it to be a drastic option. However, unlike Joanna, Carol included the addendum, "unless you've got one hell of a case for doing that". As I discussed earlier in the chapter, women constructed their accounts of decision-making to emphasise the extent to which the experience of watching loved ones develop and die from cancer, shaped their decisions. Although she had a family history of HBOC, Joanna had not observed any close blood relative develop early-onset cancer. Furthermore, she was the only woman whom I spoke to who had not experienced this, and was the only woman to decline genetic testing. Consequently, Joanna's lack of lived experience with HBOC may have shaped her opinion of the perceived positives and negatives of any intervention strategy.

Joanna's perception of the disfigurement that may result from mastectomy was influenced by the negative surgical outcomes of the elderly women who she knew, who had had breast cancer. She described how some of them had difficulty lifting their arms because the pectoral muscle was removed during their mastectomy, and she then talked at length about her mother-in-law's encounter with breast cancer. Throughout this, Joanna repeatedly emphasised what she believed was a negative side effect of breast cancer surgery:

454 Joanna: They found one lump under one arm and then another lump
455 in the other breast, so she had a double mastectomy aged
456 83, four, five something, so a traumatic operation for
457 a woman of that age, and I think they tried to dig very deep to
458 get out the first main cancer, they couldn't get it all out and
459 right up against an artery or something, erm and so one saw,
460 **she was in terrible discomfort** after the operation, and never
461 really, it wasn't, didn't, it never, because **they made such a**
462 **mess of her, she was always really uncomfortable** and it
463 was a mess, and of course in fact she died about six months
464 later, so in hindsight you could say what on earth were they
465 doing putting her through that in the first place.

Joanna, interview, lines 454-465; emphasis added.

Joanna's account highlights her beliefs about the brutality of surgical techniques and the painful consequences. She described how the surgeons dug "very deep" (line 457) when attempting to remove her mother-in-law's breast cancer, and reported that she was "in terrible discomfort" (line 460) and "really uncomfortable" (line 462). Moreover, and perhaps more significantly for a woman facing the decision whether to proceed with a test that might result in a mastectomy when she had no symptoms of breast cancer, Joanna repeatedly mentioned that the surgeons had made a "mess" of her mother-in-law's body (lines 462-463). When Joanna's earlier comment about the horrendous disfigurement that she associates with breast cancer surgery is taken into account, it is possible to observe that Joanna is presenting evidence so that her negative opinion regarding surgical intervention for breast cancer risk might be considered as compelling.

Although Joanna's account was structured to illustrate that she had two reasons for making her decision, the first rationale included many interrelated influences that shaped her decision-making. When comparing the prospect of a negative outcome from surgery, both aesthetically and in relation to the uncertainty associated with current risk-reducing techniques, with her current fit, capable body and active lifestyle, Joanna made the decision that she considered was most appropriate for her. She judged current risk-reducing techniques as not providing the certainty and aesthetic result that would persuade her to have genetic testing.

Joanna's second rationale for declining genetic testing was shaped by her anxiety that any form of genetic test may lead to future problems gaining insurance[35]. She stated:

142 Joanna: If I did have the test and I was positive then I would have
143 problems filling in any future medical forms of assur,
144 insurance forms or assurance forms, which is an
145 enormous disadvantage.

Joanna, interview, lines 142-145.

Here, Joanna constructs her account to accentuate that she is acting in a manner befitting a good, moral citizen. At face value, Joanna's second rationale for declining genetic testing is based upon the "enormous disadvantage" (line 145) involved in losing her insurance cover. However, her account has a secondary function. Her comment that she would have difficulty gaining insurance once the insurance companies were aware that she had had a genetic test (lines 142-144), implies that when asked a question, she replies honestly. Her explanation demonstrates that Joanna wishes to be recognised as a moral, ethical and decent person. Her account reveals the belief that any failure on her part to disclose her genetic test to an insurance company would be a fraudulent act. In turn, this underlines the notion that during the interview, she is providing an accurate narrative of her experience of being at-risk, rather than constructing an account which would show her in a particular light.

Joanna's rationale in defending her decision not to have genetic testing, that a consequence of undergoing testing would possibly be the difficulty in the uptake of insurance, is unexceptional both genetically and in relation to the wider field of health related decisions. Although Wright Clayton argued that, "people often cite fear of losing

[35] The concern regarding genetic information and insurance has been acknowledged (Holtzman and Shapiro, 1998). Speaking at the launch of the Government White Paper, "Our Inheritance, Our Future", Dr John Reid, Secretary of State for Health, highlighted the Government's awareness of the public's concern about the potential for genetic discrimination (BBC News Online, June 2003). The current moratorium banning insurance companies from enquiring whether customers have undergone genetic testing was established in 2001, to allow greater understanding to be developed regarding the social and ethical consequences of the new genetic technologies in relation to insurance (Department of Health, 2001). The moratorium was expected to end in 2006, but has now been extended to 2011. However, whilst it is in place insurers are not permitted to enquire whether a genetic test has been taken when "life insurance policies up to £500,000 and critical illness, long term care insurance and income protection up to £300,000" (Department of Health, 2001:4) are sought. The only genetic test that insurers are currently permitted to enquire about, for life insurance policies over £500,000, is for Huntington's disease (Department of Health, 2003).

insurance as a major reason to avoid genetic testing" (2003:563), other illnesses and diseases also have implications for insurance cover. Other examples include HIV, heart disease and cancer (Life Assurance Online, 2003), and the involvement of other agencies in health related matters is said to be a consequence of the surveillance society that we currently inhabit (Armstrong, 1995).

Joanna considered that the disadvantages of genetic testing outweighed the advantages. Moreover, she decided that "ignorance was bliss" (lines 148-9), and resolved not to discover whether she had inherited her aunt's mutated gene. Joanna's statement that ignorance is bliss is comparable with Trisha's comment in chapter five that she 'forgot' about her family history of breast cancer. Trisha's act of 'forgetting' about her risk was her way of coping, just as Joanna's decision to remain ignorant of her risk is her coping mechanism. For these two women, the desire not to dwell on their family history of disease influenced their perception regarding whether it would be beneficial for them to discover their genetic identity.

ii. Agreeing to undergo genetic testing.

In contrast to Joanna, the remaining 11 women who participated in the interviews chose to undergo genetic testing. Their stated motives for doing so included the need to resolve their anxieties and address the uncertainties they associated with being at-risk. Additionally, as previously discussed, the women discussed how their responsibilities towards their families influenced the decisions they made.

During the interviews, many of the women spoke about how uncertainty regarding what the future may hold influenced their decisions to undergo genetic testing. For example, Jill explained:

44	Jill:	I had the test done
45		because I needed to know, I'd rather know, I'd rather know and
46		be able to, to be in control.

Jill, interview, lines 44-46.

Jill's account of her decision to undergo genetic testing stresses her desire to know about what risks she might be facing. In turn, she constructs the rationale that having this knowledge would allow her to feel in control. Bouchard et al argued that most of the women presenting at genetics clinics, "were mainly interested in information concerning the risk of cancer and the possibility of early detection" (2004:1090). Although Jill's explanation that she needed to be informed meshes with the account given by Bouchard et al, it remains unclear about what she wanted to be in control of (line 46). However, Jill does not offer an immediate explanation. Rather, the issue of being in control is returned to later in the interview when Jill revisits her reasons for having testing and risk-reducing surgery. She stated:

724 Jill: **I think that is why I had the test done really because I can't**
725 **tackle something that I don't know, I can't you know, and**
726 **I'd rather face things** than, well I say I that but I am dithering
727 about having that operation, I'd rather know what I am dealing
728 with. **I wouldn't like to keep going for tests and never**
729 **knowing,** you know, like they said you could carry on and we'll
730 just watch you and I couldn't really see the point in taking, that
731 to me wasn't taking, that advantageous, I mean, I know some
732 women do that, but I, it would always be in the back of my
733 mind, you know, have I or haven't I got it, so **I needed to know**
734 **what I was really dealing with.**

Jill, interview, lines 724-734; emphasis added.

In this extract, Jill is constructing an account that enables her to be seen as acting responsibly by dealing with the risk she faces. She commented, "I can't tackle something that I don't know" (lines 724-725), and then "I can't you know" (line 725). These utterances emphasise her belief that having genetic testing was the only option that would allow her to "face things" (line 726). In doing this, she is reinforcing the notion that genetic testing was her only choice, both to herself and to the interviewer. The utterance was constructed so that the lack of any alternative choice would be emphasised. Jill constructs her rationale for the decision to undergo genetic testing to show that she was concerned to find out "what [she] was really dealing with" (lines 733-734). She postulated that this would enable her to have some control over her future. However, later in the extract she admits that her actions contradict the account that she has been building. Although Jill took control over her risk of developing ovarian cancer by having a hysterectomy, she admits that she is "dithering" (line 726)

about whether to have a mastectomy. The delay in making the decision to have a mastectomy cannot be considered as actively managing her risk. Jill's difficulty in making such a decision highlights the difference between the decision to have a hysterectomy or oophorectomy, and to have a mastectomy[36].

Like Jill, Susan considered that becoming aware of her genetic status would also offer some form of certainty. At the start of her consultation, the doctor summarised the agenda for their meeting, ending his turn by stating, "so today is about discussing your thinking" (lines 3-4). Immediately, Susan responded with the comment "I need to know if I've got the gene before I can make any decisions" (lines 5-6). However, even though the doctor then spent some time informing her that she did not need to know whether she carried a genetic mutation in order to make any decisions, Susan's initial decision (lines 5-6) remained unaltered. The first time that the doctor explicitly asked Susan whether she wished to pursue genetic testing occurred towards the end of the consultation.

108	Doctor:	Do you want to pursue genetic testing?
109	Susan:	I've pretty much decided that I would like to – I feel like I'm in
110		limbo and I've probably got it.

Susan, consultation, lines 108-110.

In answering the doctor's question, Susan's conviction in her decision is unsteady. She replies that she has "pretty much decided" (line 109) that she will undergo genetic testing. The comment that she had "pretty much decided" accentuates the argument that health related decisions could be difficult to make when a person is not experiencing any symptoms of ill health. Susan continues with her explanation, and attributes her belief that she's "probably got it" (line 110) to the experience of seeing members of her family develop cancer and also test BRCA positive. Following this explanation, her resolve to have genetic testing seems to be clearer; she commented:

[36] This is addressed in chapter eight.

115 Susan: I just **need** to know.
116 Doctor: There is an equal chance that you won't have it
117 Susan I **need** to know so that if there are any problems, I can deal
118 with it.

Susan, consultation, lines 115-118; emphasis added.

Susan's emphasis upon needing to know if she is at-risk, and her justification that this will allow to deal with any problems, echoes Jill's statement "I had the test done because I <u>needed</u> to know" (lines 44-45; emphasis added). Both Jill and Susan considered that testing would enable them to manage their risk more effectively than if they remained unaware of their carrier status. Caitlin also felt that undergoing genetic testing had given her a better opportunity to cope with and react to the threat of further cancers. Testing BRCA positive allowed Caitlin to actively manage the other risks that she faced. She explained:

252 Caitlin: I'm glad that I had it done 'cos at least now I am being
253 screened for ovarian cancer.

Caitlin, interview, lines 252-253.

Caitlin's explanation focuses upon a positive outcome of undergoing genetic testing. Uncovering her BRCA status would not alter her breast screening entitlement, but would result in her having regular ovarian screening. Although Caitlin did not mention any family history of ovarian cancer, her anxiety about the possibility of developing ovarian cancer in the future is not unexpected. As I discussed in chapter one, some BRCA carriers can develop both breast and ovarian cancer. Moreover, whilst defending her reasons for being anxious, Caitlin described how her twin sister, Amy, had been told that her ovarian screening had detected some 'abnormalities'. Like Caitlin, Amy had also developed early-onset breast cancer and had subsequently tested BRCA positive. Thus, Caitlin's anxieties regarding ovarian cancer could well have been raised after her sister's results showed some abnormalities and she feared that she would go on to develop the same problem. In providing this explanation, Caitlin is performing an act of self-protection (Goffman, 1959). She is demonstrating that she is aware that she is at-risk of ovarian cancer and is displaying that she is taking adequate steps to address this risk. Should she develop ovarian cancer later in life, Caitlin's account is constructed in

such a way to protect her from being blamed for the cancer. She had already taken all the preventative action that she could.

All of the data extracts in this section of the chapter have illustrated that women constructed their accounts of their decision-making in terms of becoming informed about their risks, and subsequently taking control of them. However, none of the women participating in this research questioned the lack of certainty associated with genetic testing. Testing BRCA positive does not result in the complete certainty that the women were searching for. Rather, genetic testing can only provide information in the form of percentages of risk. Bouchard et al commented, "predictive testing is still not a perfectly reliable instrument to know if a disease will develop, when it will develop and how severe it will be" (2004:1094). Nevertheless, for the women choosing to discover their mutation carrier status, genetic testing is currently the only option that allows them to find out the estimated likelihood that they will develop cancer.

Thus far, in this section of the chapter, I have emphasised the need of the individual to discover her genetic mutation. This is demonstrated by the continual use of 'I' within the data extracts. Examples seen include "I've pretty much decided", "I would like to" and "I just need to know" (Susan, lines 109-110), "I'm glad that I had it done 'cos at least now I am being screened (Caitlin, lines 252-253), and "I think that is why I had the test done really because I can't tackle something that I don't know, I can't you know, and I'd rather face things" (Jill, lines 724-726). Despite constructing accounts that illustrated their decisions were influenced by their obligations to others, by individualising the decision to seek testing, the women are actually revealing that it was just as important for them to take whatever action they did, for themselves.

However, as I demonstrated in chapter five, genetic risk implicates more people than just the individual being seen by the doctor or the person talking to an interviewer. Hallowell et al claimed, "none of the women……described their decision….as a decision that they made just for themselves" (2001:687). As this chapter develops, the discussion progresses to focus upon the manner in which women's accounts demonstrate that their decisions to undergo genetic testing were swayed by their need to protect (or be seen to be protecting) their daughters and siblings from developing

HBOC, lessening the chance of loved ones watching them suffer from either disease in the future, or adhering to a promise made to a terminally ill mother.

According to Novas and Rose, "the decision to undergo a predictive genetic test is presented as a monumental and potentially life-altering decision that one makes for oneself, in relation to one's genetic legacy, and for significant others" (2000:503). The notion of responsibility in relation to 'significant others', was developed by Jill, who discussed how, in addition to wanting to protect her children, she felt obligated to undergo genetic testing because her mother had asked her to do anything possible to avoid the illness from which she was dying. Jill explained:

127 Jill: **I felt like I'd got to do it for my Mum**, you know
128 and I owed it to my children as well.

Jill, interview, lines 127-128; emphasis added.

Jill emphasised that she felt duty-bound to have genetic testing because of her mother's request. Hallowell (1999) also found that a terminally ill close relative could influence women's decision-making and chosen risk management option, and used the following quotation to support her argument:

> I knew she was dying…..and the last thing that she said to me was, 'look your great grannie's dead, your grandmother's dead, your sister's dead, and I'm next on the list…..Now is the time to start making some decisions'.

Unnamed respondent cited in Hallowell, 1999:110.

These two accounts emphasise how a family history of disease can be used to manipulate, or influence women to make decisions about their risk status and take appropriate action to lessen their chances of developing disease. Moreover, Jill's explanation that she felt as if she had to have testing (lines 127-128), draws attention to her perception that she had little choice but to carry out her mother's wishes[37].

[37] During the interview, Jill described how her own referral to the Family History Clinic was dependent on her late Mother's decision to undergo genetic testing so that the family would become aware of any genetic mutation or risk that they may have.

Women's motivation for addressing anxieties about their own health is often translated into a concern to protect others. Jill constructed her account of the decision to undergo genetic testing so that emphasis was placed upon her mother's desire to ensure that she (Jill) had genetic testing. Jill's mother was reported as having acted in order to protect her daughter from developing cancer. Similarly, as discussed earlier in the chapter, Jill spoke about wanting to protect her children from watching her develop and suffer from cancer (lines 711-717). These accounts demonstrate an extension of Goffman's (1959) self-protection concept. Women explained their decision to seek genetic testing not just in order to protect themselves against future risks, but also because they felt the need to protect others. For example, Laura mentioned that she was also aware that her sister Trisha would be implicated in any decision that she reached. She said:

Laura: All I could really think about was I want to know, and if I decide not to have it done, then it would affect so many other people. **If I didn't, it would affect my sister's [Trisha] chance of having it, or my sister would have had it done but it would have taken** longer for her to have it done.

Laura, interview, 36.01 – 36.40 minutes; emphasis added.

Laura's account of her reasons for making the decision to have testing focuses upon the negative implications that not undergoing genetic testing would have upon other members of her family. Laura emphasises how the causal chain between herself having testing and Trisha subsequently being able to have testing, would have broken down if she had declined testing in the first instance (lines 3-6). As such, her decision is portrayed to be as much for the benefit of her sister as for herself. However, whilst Laura concentrated upon the possible consequences for her family if she had decided not to have genetic testing, Trisha emphasised how her sister had given her a "golden opportunity" (lines 251-252) to discover whether she carried a genetic mutation. She recalled:

Trisha: She started to get upset and **she said 'I'm really sorry, what an awful thing to, a legacy to give you' and I just looked at her and said 'what do you mean, you've given me an opportunity, I feel that you've given me a golden opportunity,** it sounds awful to say to get 'it' before 'it' gets me' I said 'that is how I feel because if you hadn't, you know, gone down the genes route, then I could be looking at something totally different, how, whatever time scale in x number of years, you know I am forever indebted to you, you know, to you for giving me this chance, and that is how I feel, you know, what a lovely thing to do.

Trisha, interview, lines 248-258; emphasis added.

This account compares the reactions of the two sisters regarding the news that Trisha might carry a mutated BRCA gene and thus be at-risk of HBOC. Whilst Laura is recounted to have said "what an awful thing to, a legacy to give you" (lines 248-249), Trisha testified that she felt as if her sister had given her a golden opportunity, a chance to "get it [cancer] before it gets me" (lines 252-253). Linguistically, the account Trisha gives is interesting; the words she uses to describe both her own and Laura's feelings oppose one another. One sister considers that her own positive BRCA test creates a damaging "legacy" for the other (Laura, line 249), whilst the other sister perceives it to be an "opportunity", a chance to react to her risk (Trisha, line 251). Moreover, Trisha constructs the account so that Laura's apparent perception that her actions created something "awful" (line 249), are contradicted by her description of something "golden" (line 251). Thus, the decision to have testing was reportedly influenced by the perception that others, as well as the woman herself, would benefit.

As these last data extracts illustrate, the justification to discover one's genetic risk regularly involves the desire to protect third parties. The need to protect others was continued when women again spoke about the influence that their children had upon their decision-making. Although many of the women constructed their talk so that their efforts to protect their children from both being at-risk themselves, and from watching their mother develop cancer, were visible, it appears that women were more concerned about the chance that their daughters might have inherited the mutated gene and would go on to develop cancer later in their lives. Only a minority of the women mentioned the risk posed to their sons. Zoë explained how she worried about her daughter Amy and was relieved to discover that the baby she was carrying was male:

408	Zoë:	I'm worried about Amy as it is, it's on my mind
409		every day [……..]
412		[but] we found out yesterday that [this one is] a boy, so we can
413		relax a bit.

Zoë, interview, lines 408-409 and 412-413.

Zoë is careful to reinforce that the risk to her daughter is "on [her] mind everyday" (lines 408-409), and in making this statement, is illustrating that she wants to be recognised as a good mother who is shielding her daughter from the risk that she could have passed onto her. Contrasting this, the last two lines of data, "we found out yesterday that [this one is] a boy, so we can relax a bit" (lines 412-413) demonstrate her happiness and relief that the child she is carrying will not face the same risk.

When talking about the risks that their BRCA mutation might have for their children, the women did not talk about the risk that the mutation poses to their sons without being prompted by the interviewer[38]. For example, in the above extract, Zoë does not even address the risk that her positive BRCA status has for her eldest son. A similar situation arose during Joanna's interview. Having spoken about the potential risk to her daughter, I then asked Joanna about the risks faced by her sons:

620	Emma:	Have you discussed this [being at-risk] with your sons?
621	Joanna:	I don't think I really have. I suppose the emphasis from the
622		clinic was not particularly on the prostate side.
624		No one is saying to me 'have you got sons?' and 'you must talk
625		to your sons'.

Joanna, interview, lines 620-622 and 624-625.

The link between the BRCA genes and prostate cancer is widely reported (Bennett, Taurog, and Bowcock, 1999). However, Joanna does not comprehend why she should talk to her sons. Moreover, she is not alone in failing to acknowledge or understand the risks posed to her sons. Kenen et al (2003b) referred to one of their respondents whom

[38] Although male breast cancer is rare (Perkins and Middleton, 2003), men found to carry a positive BRCA2 gene are at greater risk of developing breast cancer and have a higher susceptibility to prostate cancer (Bennett, Taurog and Bowcock, 1999). Several factors may shape women's lack of awareness of the risk for men. It is possible that BRCA related risks for men are not being adequately addressed or emphasised enough within the consultations. Breast cancer has been so widely depicted as a female killer (Cancer Research UK, 2002) that people may be unaware that men too can develop the disease, and subsequently cannot recall being given any risk information about the dangers that men face in relation to breast cancer.

they named “Doris”. Whilst discussing whether to undergo genetic testing, Doris is reported to have argued that she did not need to have testing as she only had sons, and “realistically it’s normally a woman” who develops breast cancer (Kenen et al, 2003b:851).

Joanna’s account is constructed to emphasise that because she herself was unaware of the associated risks, she could not share this information with her sons. In responding to my question (line 620), Joanna explained, “I suppose the emphasis from the clinic was not particularly on the prostate side” (lines 621-622). By raising the question, I may have prompted Joanna to take a defensive stance; Joanna may have felt compelled to explain why she has not discussed being at-risk with her sons. As such, the explanation that she offers acts to preserve the image of herself that she has been constructing. She immediately responds by protecting herself from any blame by defending her inaction, stating, “no one is saying to me ‘have you got sons?’ and ‘you must talk to your sons’” (lines 624-625). Joanna is careful to establish that it is not her opinion that her sons were not at-risk and that she subsequently did not have to inform them about any possible risk. Rather, she is implying that no one at the hospital had spoken to her about the risk that her sons might have inherited. Baruch (1981) argued that patients will defer to those who occupy the ‘medical reality’. Consequently, patients often consider that the medical information they are given by health professionals is “binding and final” (Baruch, 1981:281). Thus, if the hospital staff only mentioned the possible risk to her daughter, as Joanna has described, and a similar stance to Baruch is taken, then Joanna had no reason to question the medical information that she was given.

One of the greatest influences upon women’s decisions whether or not to undergoing genetic testing were the obligations and responsibilities towards their children, mothers and siblings. Hallowell (1999) commented:

> it has been observed that individuals not only have a responsibility to avoid voluntarily exposing themselves and others to health risks, but also may be seen as bearing some responsibility for their genetic risks.
>
> Hallowell, 1999:98.

However, although women have rationalised their decisions in relation to minimising the risks posed to others, developments in both molecular genetics and the health promotion movement have led to claims that health and disease are an individual's responsibility. Whilst this chapter has shown that women have constructed accounts of their decision-making so that any blame for subsequent negative outcomes will be deflected away from themselves, the guilt at being the person to pass on the genetic mutation to future generations remains. Although genetic medicine involves the biological family, genetic risk and the associated biologico-moral responsibility, it has become an individualised phenomenon.

Upon hearing that she had tested BRCA positive, Laura explained that she felt guilty, because she was the person who put her daughters and niece at-risk. She said:

1 Laura: I'd got all the female children in the family [with me] and
2 every time I looked at them, I thought 'oh god, I've passed
3 on this horrible thing to them'.

Laura, interview, 39.00 – 39.20 minutes.

Whilst telling me this, Laura started to cry. Laura's emotional account here mimics the comments that Trisha recounted that Laura had made when she told her that her positive test would mean that she might also be at-risk (lines 248-258, page 195). Again, Laura is seen to blame herself for others being at-risk. Steinberg considered that women have been constructed as "the bearers of nature's defects [and as] gene transmitters" (1996:267), regardless of from whom the mutated gene had been inherited. Laura's guilt at testing positive and what the test result might subsequently entail for her children, is one such example of the gendering of genetic responsibility. Furthermore, it also illustrates a negative repercussion of genetic testing. Although interventions to reduce risk can be made, uncovering one's BRCA status also implicates others.

Douglas proposed, "a culture needs a common forensic vocabulary with which to hold a person accountable" (1990:7). The term chosen to explain this was 'risk'. It was argued, "to be placed 'at-risk' is equivalent to being sinned against" (Douglas, 1990:7). Therefore knowingly placing another human being at-risk might be considered to be a sin, as "being 'in sin' means being the cause of harm" (Douglas, 1990:7). In these

terms, the guilt that the women reported that they felt regarding whether they had passed on a genetic mutation to their children, would signify that they be recognised as sinners and the children, the sinned unto. The following account illustrates that once she knew that she carried a positive BRCA mutation Trisha questioned her yearning to have a family. She stated:

Trisha: I suppose personally I found it, the difficult thing that, from being a young girl…. **I had always wanted my own little family and that was the point that I sat down and thought 'what have I done, what have I done?' I never ever questioned having children until that moment, and you know, I felt very guilty, I felt very awful that I might have passed this dreadful thing onto my children, mmm** and I think another thing as well, another memory that it has brought back to me was um, when I was having Emily I sort of thought, oh well wouldn't it be lovely to have one of each and err obviously **when they placed this baby in my arms and told me 'it's a girl' it was like I had won the lottery, I felt so elated, but then I really felt like my balloon had popped that maybe it would have been better for her to be a boy…I think for me that was the lowest point**, for me that was the realisation, that was the awful point.

Trisha, interview, lines 191-205; emphasis added.

Trisha's account is constructed so that her anxiety regarding passing her mutation onto her daughter is emphasised, and thus reinforces Douglas' argument that those placing others at-risk are sinful. Trisha's description of facing the prospect that her daughter may have inherited her mutated gene, captures both her feelings of guilt because of placing her child at-risk, and also adds to the image of the responsible mother that she had been cultivating throughout the interview. Moreover, Trisha's desire to be perceived as a good mother, and protecting her children despite her own needs is furthered. During the interview, Trisha explained that she had always wanted a daughter. However, reflecting upon her desire to have a daughter, in light of the news that she is BRCA positive, Trisha felt that "maybe it would have been better for her to be a boy….I think for me that was the lowest point" (lines 203-204). Again, the protection of others is weighed against the women's own interests. It is also a further example of women perceiving that they need only to protect their daughters from being at-risk, rather than also being concerned about the risks posed to their sons.

Laura offered an additional example of how women react to news that they carry a BRCA mutation. Although Laura discussed how she felt guilty and to blame for placing others at-risk during the interview, her account differs when talking about her breast cancer, which was diagnosed prior to being told that she carried a mutated BRCA gene. Laura used the presence of a mutated gene to construct an alternative view regarding who, or what, was to blame for her developing cancer:

1 Laura: I know this probably sounds really selfish, but **I was looking for**
2 **a reason that would say it's not your fault,** you know, it's not
3 because I didn't eat my broccoli when I was younger.

Laura, interview, 36.41-36.59 minutes.

The account that Laura gave illustrates her relief that her mutated gene was responsible for her developing breast cancer, rather than it being something that she did or did not do. In providing such an account, she is explaining away the individualisation of risk and refuting any claim that she is at fault. Laura's account provides a further example of how the explanations women offered were created so that they functioned as a means of self-protection.

7.4. Exceptional decisions?

In this chapter I have illustrated that women constructed their accounts of decision-making to demonstrate that many factors influence the decision to either decline or undergo genetic testing. These rationales were varied and ranged from having an obligation to protect their children, to carry out their mother's wishes, wanting to know what they faced, and to be able to be in control. In light of the similarities in the accounts of decision-making given by the women I interviewed, and those Murphy (1998, 2000, 2003) reported whilst examining women's decisions regarding whether to breast or bottle feed their babies, I have reached the conclusion that the rationales given to justify the decision whether to undergo genetic testing are no different from those received when justifying any decision that could have an impact upon another person's life. Support for the genetic exceptionalism thesis is therefore not given.

The next chapter develops the focus upon women's accounts of their decision-making, and concentrates upon the decision to undergo risk-reducing surgery.

Chapter Eight. Surgical Decision-Making.

> 'One of the worst things about this is you don't feel like a woman,' she said….
> I wanted to comfort her. Her completeness as a woman was finished.
>
> Reibstein, 2002:77.

In the previous chapter I examined women's decisions regarding whether to undergo genetic testing, which would enable them to discover whether they carried a mutated BRCA gene that would signal a predisposition to HBOC. Women found to carry a mutated BRCA gene were asked to make a second decision, namely whether to have risk-reducing, prophylactic surgery. The majority of the women who carried a mutated BRCA gene chose to pursue elective, prophylactic surgery. However, Jen and Jade alone chose extensive surveillance as their risk management option. As I discuss in this chapter, women's rationales for both declining and undergoing risk-reducing surgery drew upon perceptions that the surgery was either elective or essential, the differences between a mastectomy and an oophorectomy or hysterectomy, and how they considered that surgery was the most effective way of reducing their risk of HBOC[39].

In chapter one I noted that the medical profession's favoured option for reducing women's risk of developing HBOC is bilateral prophylactic mastectomy and prophylactic oophorectomy or hysterectomy. However, whilst surgeons favour these procedures, there is no consensus regarding the most effective manner to reduce risks (Kenny et al, 1999). Whilst some doctors favour surgical intervention, others advocate extensive screening or chemoprevention. Thus, patient participation in surgical decision-making is advocated. Kunkel et al (2002) explained:

> increased emphasis on the woman's participation in medical decision-making has afforded her more treatment options. [However], it also gives her more responsibility in determining the course of treatment through the continuum of cancer care.
>
> Kunkel et al, 2002:129.

[39] In chapter seven, I discussed how many of the women also defended their surgical decision-making in terms of the responsibilities inherent in being a mother.

In this chapter I demonstrate that many of the women reported that although the decision to have their breasts removed was difficult to reach, they felt as if there was no alternative choice that would reduce their risk of developing HBOC to the same extent as surgery. Moreover, their accounts also demonstrate the difficulties they felt regarding their responsibility for making a decision that would be acceptable for themselves, their spouses and their children.

This first section of this chapter addresses women's accounts of their surgical decision-making. In doing so, it asks four questions.

8.1. Is prophylactic surgery understood to be elective or essential?
8.2. How do women perceive mastectomy and oophorectomy?
8.3. Is surgery a means of controlling risk?
8.4. What explanations are given to rationalise the decision to delay or decline surgery?

Robertson (2001) proposed that people at-risk inhabit a state of being where you are neither ill nor healthy, whilst Duncan et al referred to the "liminal state of the potentially ill" (2001:169). Kenen added to the list with the description of the "potentially sick" (1994:49). For this reason, I begin this chapter with the proposal that having surgery when you have no signs of disease might be considered to provide an example of genetic exceptionalism.

The rise of surveillance medicine (Armstrong, 1995) has enabled the medical profession to view health and illness as stages upon a continuum that require different levels of intervention. Kenen et al argued, "we have entered the age of surveillance medicine that targets everyone, problematicizes what is meant to be normal, and fundamentally remaps the spaces of illness" (2003a:317). However, for patients, health and disease are distinct from one another and represent different experiences. Foskett reasoned, "the traditional conflation of biomedical knowledge with truth and objectivity means that the profoundly social and constructed nature of such knowledge is often overlooked, ignored or denied" (2000:18). However, the problematic status within the health-illness continuum of women at-risk of HBOC draws attention to the socially constructed nature of definitions such as illness, health and disease.

Dingwall claimed, "for sociologists, there can be no such things as 'essential illnesses'; rather, there are sets of socially organised events organised by members of a collectivity into categories of experience to which the identification 'illness' is accorded. These have no necessary relationship to any biological happening" (2001:25). Following Dingwall's suggestion, it is argued that the women who participated in this study had no "biological happening" to their 'illness'. Rather, by reacting to the "socially organised events" following diagnosis of a positive BRCA mutation, the women were identified as inhabiting not a state of illness per se, but a state of risk. In turn, this identification enabled each woman to seek medical intervention that was orientated towards reducing, or managing her risk.

8.1. Is prophylactic surgery understood to be elective or essential?

To be identified as 'at-risk' places a woman in an unusual situation, which in turn produces unusual consequences. Women at-risk of HBOC are asked whether they wish to have surgery to reduce their risk of developing breast and/or ovarian cancer, even though no cancerous cells are likely to be present. Being asked to choose whether you wish to undergo invasive surgery is not usually an option presented to patients in other medical specialisms. In general, surgery is performed when a consultant decides that there is a clinical need[40]. Moreover, the clinical need is most likely to have been established in light of the patient experiencing symptoms of ill health. For example, although patients who are diagnosed with tonsillitis will usually be asymptomatic at the point of surgery, symptoms will have been experienced in order for the patient to seek intervention in the first instance. Thus, whilst being asked if you would like to have surgery is unusual, deciding to undergo surgery when you have experienced no symptoms, like the women in this study, is all the more exceptional. Furthermore, women were reacting to a threat of cancer, rather than its presence. It is not just that they were asymptomatic, but that they had no signs of disease. Consequently, these decisions can be problematic and difficult to make. Zoë stated:

[40] Throughout this thesis, such surgery is termed 'essential'; I have made a conscious decision not to use the term 'compulsory', as patients have the right to decline to sign an informed consent form, which thus removes the compulsory nature of such surgery.

783 Zoë: I feel brave for going through the operation, ‘cos **when**
784 **you’re ill you have an operation**, like I’ve had my
785 wisdom teeth out, or if you have a burst appendix like
786 Richard [partner] had, you know, **you <u>need</u> to have the**
787 **operation.**

Zoë, interview, lines 783-787; original emphasis underlined; added emphasis in bold.

Zoë’s account of her reaction to her decision to have prophylactic surgery stresses the distinction between the states of illness and health. She compares her operation to having her wisdom teeth removed, or her partner’s appendectomy. She perceives that both these procedures ‘needed’ to be performed, and contrasts this with her decision to have a bilateral prophylactic mastectomy even though she had no signs of disease. In essence, Zoë is drawing a distinction between what she considers to be essential and elective surgical procedures. Moreover, earlier in the interview, Zoë had already questioned whether the operation was a clinical necessity:

171 Zoë: **You sit there and think you’ve had an operation**
172 **that you didn’t really need to have**, I mean, I could have
173 waited I could have waited for another ten years, I suppose I
174 kind of thought, you just press the panic button and think just
175 get them off, I don’t want to look like me Mum.

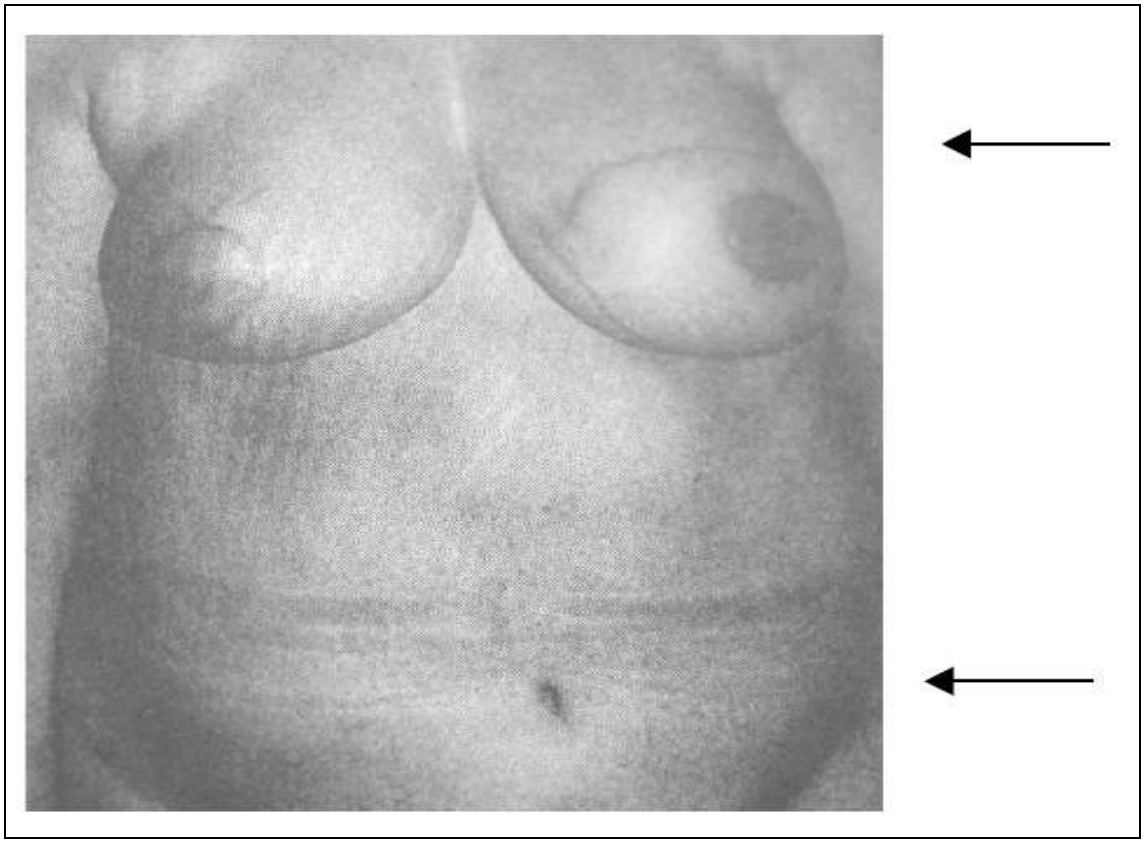
Zoë, interview, lines 171-175; emphasis added.

Zoë’s account is structured so that her opinion that she “didn’t really need to have” the operation is emphasised (line 172). In doing this, she is drawing attention to the non-compulsory nature of undergoing prophylactic surgery. She is demonstrating that she took action against her risk and had an operation, usually associated with breast cancer, despite no cancerous cells being present. She defends her decision by stressing her belief that she acted in an appropriate and responsible manner in order to alleviate her risk. Her statement, “I could have waited for another ten years” (line 173), reinforces this. The previous two data extracts display how Zoë views the distinction between essential and elective surgery; the appendectomy was essential (line 785) whilst her mastectomy could have waited (line 173). However, although she makes this distinction, one of her rationales for undergoing surgery was influenced by her observation of the possible visual outcome of breast disease and mastectomy due to a malignant tumour. In line 175, Zoë explains that she chose ‘elective’ prophylactic

surgery because she did not want to look like her mother, who had been diagnosed with breast cancer. Here, Zoë is implying that by choosing to have prophylactic surgery, she would receive a more favourable aesthetic result compared to that if the procedure was carried out to remove a tumour. Depending upon the technique used, prophylactic surgery can result in less scarring compared to radical mastectomies.

The following two images depict the typical aesthetic outcome of a TRAM flap reconstruction following breast cancer, and a reconstruction using saline implants, following a prophylactic mastectomy. In figure 18, the image of the TRAM flap reconstruction illustrates the scarring that can result. The arrows highlight where the woman is heavily scarred across her abdomen, from where the skin graft to construct the breast was removed, and again on the left breast, where the re-constructed breast has been attached.

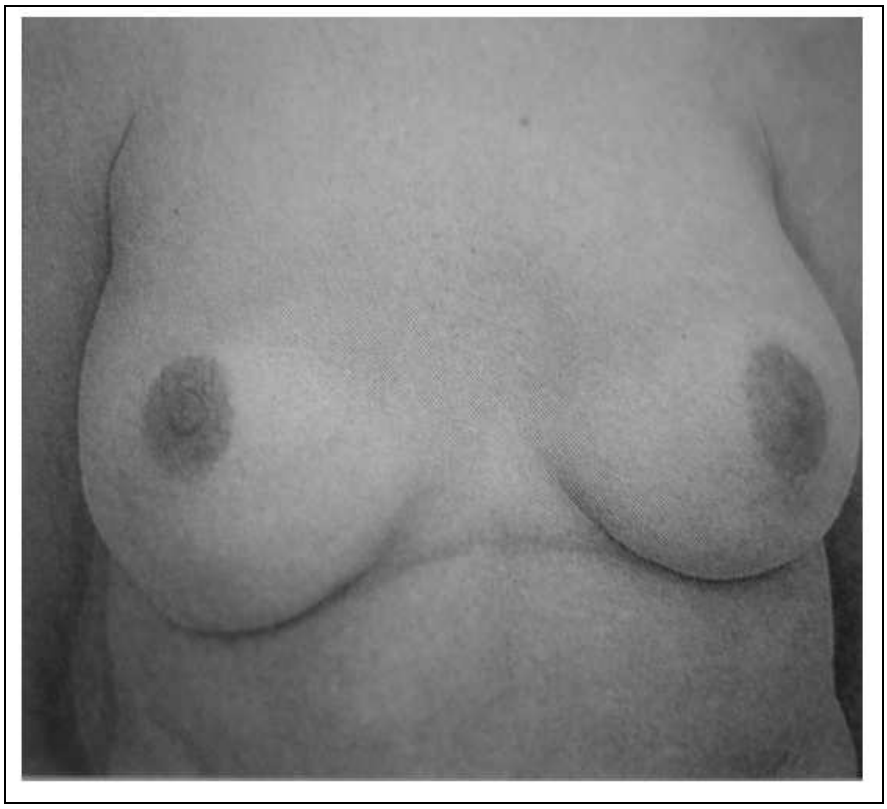
Figure 18: The aesthetic outcome of the TRAM flap technique.



Source: Berger and Bostwick, 1998:289.

In comparison, the second image depicts a more favourable aesthetic outcome; the breast is reconstructed using saline implants, and very little scarring is visible.

Figure 19: The aesthetic outcome of reconstruction using saline implants.



Source: Berger and Bostwick, 1998:363.

These images demonstrate the varying aesthetic outcomes of mastectomy performed to remove a cancerous tumour (figure 18), compared to that performed prophylactically (figure 19), and secondly, the differences in the reconstruction method utilised.

The impression that prophylactic surgery is somehow different to essential surgery can be observed in other accounts. Upon hearing that she carried a positive BRCA mutation, Jill chose to have a hysterectomy. The procedure enabled the threat posed by her ovaries and the risk that their hormone production created, to be alleviated. However, she stopped short of reducing all her risk, and chose not to have a prophylactic mastectomy. Jill explained why she was delaying making the decision whether or not to have a prophylactic mastectomy:

156 Jill: **I don't feel like I've got cancer and I think that is another**
157 **reason why it is very difficult to go down the surgery**
158 [route], is that when you are healthy, you know, it is, it just
159 feels like self-mutilation. I know that is a very strong word, I
160 think, but that is how it feels you know, it's not nec, it's not
161 necessary but I don't think, **who wants to go through with**
162 **an operation when its not, when you're not ill sort of thing?**

Jill, interview, lines 156-162; emphasis added.

Jill rationalised her decision not to have a mastectomy in terms of not feeling ill (line 162) and not feeling like she had cancer (line 156). In providing this explanation, Jill like Zoë, is contrasting a surgical procedure carried because of an essential clinical need, with elective surgery performed to reduce the risk of developing a disease. Moreover, her account is constructed in such a manner that it demonstrated an example of Goffman's (1959) argument that self-presentation acts as a form of self-protection. Jill's justification for declining surgery plays upon the absence of any symptoms or signs of disease. Her account is structured so that her actions, despite contradicting medical opinion, are understood to be the result of a rational choice. She is not obligated to have surgery because she does not consider that she is diseased. However, Jill's belief that it is unnecessary to have a prophylactic mastectomy contrasts with her decision to have a prophylactic hysterectomy. The next section of the chapter moves to address this discrepancy via a discussion of women's own assessment of the differences between breasts and ovaries, and mastectomy and oophorectomy.

8.2. How do women perceive mastectomy and oophorectomy?

Saywell et al (2000) argued that breast cancer is a grotesque disease that has the ability to mutilate bodies. Moreover, they considered that the invasive surgically orientated nature of breast cancer treatments represent a "violation of femininity" (Saywell et al, 2000:38). However, ovarian cancer and its treatment are rarely described in such terms. Nevertheless, like breasts, ovaries also form an integral part of women's gender identity, both through their hormone production and as reproductive organs. Despite this, they are perceived differently.

The data collected during the interviews suggests that choosing to undergo a prophylactic hysterectomy or oophorectomy may be an easier decision for some women

to make, compared to the decision to have a mastectomy. Several reasons for this exist. Unlike mastectomy where the breast is visible, the ovaries are concealed internally, and are thus hidden from view. Secondly, as Joanna's explanation in chapter seven demonstrated, women may be under the impression that breast tumours can be easily detected. Comparably, ovarian tumours are hard to detect. Moreover, whilst breast cancer survival rates are high, the five-year survival rate for ovarian cancer is low. Recent statistics describe a five-year survival rate, following ovarian cancer, of just 29.2% (Cancer Research UK, 2002a). The equivalent five-year breast cancer survival rate is 73.7% (Cancer Research UK, 2004). Thus, it would appear that the decision to undergo prophylactic oophorectomy might be influenced by two factors. Firstly, ovarian cancer risk may be perceived as presenting a more acute problem. Secondly, because the scars of oophorectomy or hysterectomy remain concealed, women find this surgical decision easier to make. For example, Kasper (1995) recalled the account given to her by one respondent, whom she named Catherine B:

> 'cancer was not my first worry. Just mutilation was my first worry'. She recounts that she had a hysterectomy a number of years ago and says, 'but that kind of loss is not a visible loss. It isn't body mutilation'.
>
> Kasper, 1995: 209.

Catherine B's explanation of her rationale for undergoing a hysterectomy includes reference to the invisibility of the operation, and that the outcome would not leave her looking or feeling mutilated. Berchuck et al (1999) commented that:

> most women do not view removal of the ovaries as cosmetically mutilating, and oophorectomy causes only modest changes in body-image and self-esteem.
>
> Berchuck et al, 1999:2521.

Published accounts of women's surgical decision-making have emphasised, "our society's vision of femininity is not tied up with what's inside, it's what's on the outside" (unnamed respondent, Hallowell, 1998:270). Removal of the ovaries is not considered to mutilate one's femininity, as feminine characteristics are dependent upon external appearances. Whilst the uterus was the "primary definer of womanhood" in the 19th century (Webster Barbre, 2003:275), this is no longer so. Breasts have replaced the female reproductive organs as the primary definer of womanhood.

Saywell et al described how "breasts are iconic of both female sexuality and maternity, and as such, are often the currency through which feminine value is attributed" (2000:11). Consequently, the shift in which body organ is fundamental in defining or losing one's femininity, may account for why women found the decision to have an oophorectomy easier to make than the decision to have a mastectomy. Referring to the possibility that she might have to have her ovaries removed, Zoë commented:

444 Zoë: They don't bother me. It's inside, you don't, I think when you've
445 been through the outside sort of thing, then inside, well (shrugs).

Zoë, interview, lines 444 – 445.

Zoë's explanation demonstrates the different values that women place upon internal and external body parts, and echoes the comments made by Hallowell's (1998) unnamed respondent cited above. However, Zoë's account also compares the decision to have an oophorectomy with her decision to have a prophylactic mastectomy. She implies that when you have already chosen to have your breasts removed, the decision to lose your ovaries is less problematic (line 445). Like Zoë, Cassie also found the decision to have a mastectomy to be different from the decision to have an oophorectomy. She recalled:

1 Cassie: For me, I thought that it was only ovarian that I was at-risk
2 of, so therefore, erm, I didn't think that it was going to be
3 such a major decision and I just thought it was my ovaries,
4 and my kids are in their 20s and it didn't matter to me to
5 lose that side. Erm, it became a major then, with both
6 breasts and ovaries. It was a harder decision to make then.

Cassie, interview, 5.08 – 05.48 minutes.

Cassie's account clearly illustrates how women perceive the loss of their ovaries and breasts differently. She considered her ovaries to be tools whose function had ceased, because she had completed her family. She states, "I just thought it was my ovaries and my kids are in their 20s and it didn't matter to me to lose that side" (lines 3-4). However, she explained that when she learnt that a mastectomy would also be an appropriate risk-reducing measure, the resulting decision was much harder to reach (line 5-6). Whilst Cassie justified her oophorectomy in terms of the redundant nature of her ovaries, she did not refer to her breasts in superfluous terms. Thus, having them removed was an altogether harder decision to make.

Cassie's account demonstrates that for some women the removal of their ovaries once childbearing has finished appears to be a more favourable and acceptable risk-management option than mastectomy. As Berchuck et al (1999) described, oophorectomy can have less of an impact upon a woman's self-image, as the tissue removed is concealed and does not therefore outwardly alter the woman's appearance. Additionally, although oophorectomy results in the surgical and premature onset of the menopause, the cessation of menstruation is a naturally occurring event that all women expect. Consequently, women may perceive the procedure to be less damaging to their sense of identity as a woman, compared to the impact that losing their breasts may have.

Judy had already chosen to have a hysterectomy prior to discovering she carried a positive BRCA gene. Following her diagnosis, it was recommended that she also have a mastectomy, which she found very upsetting. Judy described how she literally felt "gutted" (Judy, interview, 10.00 minutes) when the doctor had recommended that she should lose her breasts in order to reduce her risk of developing breast cancer. Her recollection that she felt "gutted", whilst an accepted colloquial form of speech, allowed her to demonstrate the gravity and depth of her reaction to the news. This was further emphasised as Judy started to cry at this point in the interview. Despite being told that she should have a mastectomy two years before I interviewed her, Judy was still traumatised and deeply upset about it.

Like Judy, Jill also had a hysterectomy but had delayed the decision to have a mastectomy. She too found the idea of a prophylactic mastectomy troubling. Explaining why she was reluctant to undergo a bilateral prophylactic mastectomy, Jill stated:

59 Jill: I keep putting off having the mastectomy because I just, I
60 dread that (…)
66 (…) I am struggling mentally with that, I feel I am going to be
67 mutilated, there is that fear, and the fear of not liking myself
68 after.

Jill, interview, lines 59 - 60 and 66-68.

Like the first rationale that Joanna gave for declining genetic testing (see chapter eight), Jill also referred to the possible mutilation that might result from breast cancer surgery in explaining her reluctance to have a mastectomy. Jill's account emphasises her fear of

the aesthetic outcome of the surgery, commenting that she had a fear of "not liking myself" (line 67) after she had had her breasts removed. Harcourt and Rumsey reinforced this, describing how, "mastectomy can be especially difficult since these women face the distress and disfigurement caused by the loss of the breast in addition to the fear of a potentially life-threatening disease" (2004:106).

Despite her explanation that she was fearful of the outcome of surgery, Jill creates her account so that it appears that it is just a matter of time before she makes the decision to have a mastectomy. She stated, "I keep putting off" the decision (line 59). In making this statement, Jill is constructing her explanation so that the inference that the decision is inevitable can be acknowledged, despite the actual language she used suggesting otherwise. Thus, it is suggested that Jill constructs her rationale so that she is seen to be following medical advice. Rather than dismissing medical knowledge and not addressing her risk, as not having a mastectomy would mean, she constructs her account so that she is seen to take all the precautions possible to reduce her risk of developing cancer. Jill wants to portray herself as responsible and so produces her account so that the person in receipt of the talk is under the impression that she will consent to undergo surgery at some point. In constructing this image, Jill is actively managing her self-image (Goffman, 1959). Her account depicts the image of a responsible consumer of health care, who is reacting to her risk and taking all available risk-reducing measures. In accomplishing this, her account functions to protect her from any criticism that she might be acting irresponsibly by delaying, or declining having a mastectomy.

8.3. Is surgery a means of controlling risk?

In chapter seven I argued that women's perceptions of the obligations to their mothers and children were influential upon their decisions to have genetic testing and undergo surgery. In this section of the chapter, I address a further influence upon women's surgical decision-making, the desire to reduce their risk. Price and Shildrick stated:

> one of the central themes of feminist activism within health has been the call for women to 'take control of our bodies'.
>
> Price and Shildrick, 1999:146.

For women at-risk of HBOC, prophylactic surgery offers a means of gaining control of their risk and their bodies. Lerner (2001b) suggested that by undergoing prophylactic surgery, women had chosen life over death. Yalom extended this suggestion and argued, "women have been obliged to confront the powerful meanings breasts convey as life-givers and life-destroyers" (1997:8). However, the women participating in this study did not voice their justifications to undergo risk-reducing surgery in such a delineated manner. Rather, like Hallowell, once they discovered they were at-risk of HBOC women perceived their "genetic bodies [to be] dangerous bodies" (2000:160) and their breasts became sites of risk. Any action subsequently taken, was to control or eliminate their risk, rather than choose between life and death.

Hallowell (2000) discussed how once they had become aware of their risk status, women perceived their bodies to be dangerous. Referring to "out of control bodies" and "biological time bombs" (2000:162), Hallowell argued that women believed that prophylactic surgery would alleviate the dangerousness posed by their breasts and ovaries. However, the notion that bodies were out of control and that surgery alleviates danger negates the idea that risk-reducing surgery is elective. Rather, surgery is required to resolve the threat that cancer might develop. Justifying her decision to have a prophylactic surgery, Trisha commented:

292	Trisha:	I look at my Mum and I look at Laura [sister] and I think, you
293		know, probably the words 'timebomb stuck to your chest ready
294		to go off' springs to mind, you know. **I didn't feel that it**
295		**was something that could have waited.**

Trisha, interview, lines, 292-295; emphasis added.

Trisha's opinion that surgery was not "something that could have waited" (line 295), centres upon her fear of developing cancer. Referring to her family history in which both her mother and younger sister had been diagnosed with breast cancer, Trisha's account is constructed to emphasise her belief that prophylactic surgery was necessary rather than optional. Trisha believed that by undergoing a bilateral prophylactic mastectomy the "timebombs stuck to [her] chest" (line 293) would be defused and thus the risk posed would be reduced. However, other women continued to worry that surgery would not provide the relief or certainty longed for. Jill believed that even if she

did have risk-reducing breast surgery, it was inevitable that she would develop cancer at some stage in her life. She explained:

686 Jill: I don't actually feel that having them [breasts] removed will
687 stop me from getting cancer because I feel so programmed
688 into having it, I feel that it will have me, but on saying that,
689 I feel that I've given myself the best opportunity, the best
690 possible chance to hold it off for some years

Jill, interview, lines 686-690.

Jill constructed her explanation so that it functioned to continue her defence of the decision to delay making a choice regarding whether to have a prophylactic mastectomy. Within her account she draws attention to her fear that cancer will develop, regardless of the surgery (lines 687-688). While not questioning the efficacy of surgery as Joanna did (see chapter seven), Jill does question whether preventative surgery can override her genetic destiny. She describes how her hysterectomy, and mastectomy should she choose to have one in the future, are a form of insurance that allow her to be in control of the risk. However, she believes that they will not deter cancer from developing. She recalled:

719 Jill: To an extent [it is] an insurance policy if you like, but erm, I
720 probably don't really look at it like that. I think if anything, it
721 buys me time, erm, it does buy me some time and it does put
722 me in control, I'm in the driving seat.

Jill, interview, lines 719-722.

When rationalising her decision to undergo genetic testing, Jill drew on the notion that being informed would enable her to feel in control. Jill again draws upon the same subject, and describes how surgery will put her in the "driving seat" (line 722). Within this account, surgery is depicted as a means of gaining empowerment, being active and fighting the risk associated with being BRCA positive. However, such a stance is juxtaposed by Jill's reluctance to have a prophylactic mastectomy. Although she perceives her hysterectomy to be a form of insurance policy against developing ovarian cancer and allows her to regain control over the threat of ovarian cancer, the same cannot be said for her risk of developing breast cancer. Rather, by delaying making the decision to have a mastectomy Jill, and Judy like her, could be exposed to the criticism

of acting irresponsibly. Despite being offered all the available intervention, they had not taken all the steps possible to reduce their risk and regain control of their dangerous genetic bodies. Moreover, their actions had contradicted medical advice.

The notion of being in control had an influence upon the accounts that Zoë and Louise gave regarding how they reached the decision to have a mastectomy[41]. Both women spoke about how once they became aware that they might be at-risk, they became paranoid about checking for breast lumps. Louise explained:

89 Louise: It was always there and I was constantly checking
90 myself every night. I'd go to bed and I'd be checking myself,
91 you know, I know they say once a month, but you just can't
92 help yourself, you've just got to. I was absolutely paranoid.

Louise, interview, lines 89-92.

Central to Louise's justification that she would have undergone a mastectomy is the idea that risk is omnipresent. Consequently, Louise uses her account of her decision-making to suggest that she could not be held responsible for "constantly checking" her breasts (line 89) and going against medical opinion which advises that women should perform self-breast examinations only once a month (Berger and Bostwick, 1998)[42]. Louise portrays her actions as being beyond her control, and explains that the threat of breast cancer was so strong that she became paranoid. A prophylactic mastectomy is represented to be the only way that the threat and the paranoia would be eliminated.

These data excerpts have illustrated that undergoing prophylactic surgery allowed the women to believe that they had gained some control over the risks created by their breasts, ovaries and mutated BRCA genes. Moreover, surgery offered them some respite from the constant anxiety related to being at-risk of HBOC. Therefore, for many women, the decision to have prophylactic surgery was unavoidable; they simply felt that they had no other choice. Cassie stated:

[41] Although Louise tested BRCA negative and did not therefore require risk-reducing surgery, she reported that she had decided to have a prophylactic mastectomy had she been found to carry a mutated BRCA gene.

[42] At the time the fieldwork was performed, guidelines suggested that breast self examination should be carried out monthly. However, guidelines have now altered, and it is recommended that women should be 'breast aware' rather than perform routine self examination (NHS Cancer Screening Programme, 2003).

Cassie: I think that is why I had the operation, 'cos how could you live with yourself if you've got the gene, don't do anything about it, and then you go and get it?

Cassie, interview, 32.27-32.30 minutes.

As this data extract exemplifies, Cassie felt that she had no alternative but to consent to risk-reducing surgery. She felt that if she had subsequently developed cancer, and had known about her risk but chosen not to do anything to lessen it, she would be accountable and to blame for the cancer and its consequences. Charles et al discussed cases comparable to the account given by Cassie, and maintained that:

> when the options presented were limited to 'doing something' verses 'doing nothing', most women did not perceive this as a meaningful choice; rather, they felt that their illness gave them no choice but to undergo treatment.

Charles et al, 1998:77.

For women both at-risk of breast cancer (as illustrated in this study) and women with breast cancer, as those involved in Charles et al's study were, surgery "was perceived not so much as a choice but rather as the only decision that they could make in order to allay any feelings of doubt that they could have done more" (1998:78; emphasis added). Therefore, despite being seen to offer at-risk women choice and an opportunity to reduce their risk, it is almost as if women feel that they have no choice but to have genetic testing and undergo risk-reducing surgery. In the minority of cases where women chose not to follow these options, they had, unsurprisingly, to construct well-prepared defences to justify their decisions, as Jill's accounts discussed in this chapter demonstrate. Thus, whilst the rationales for the decision to undergo risk-reducing surgery given by the women were diverse, the belief that surgery was inevitable was widespread.

8.4. What explanations are given to rationalise the decision to delay or decline surgery?

> If it's not broke don't fix it.
>
> Hallowell, 1998:268.

Two of the women I interviewed, Jen and Jade, chose not to undergo any risk-reducing surgery when they received the news that they carried a mutated BRCA gene. As I have already discussed, a further two women, Judy and Jill, chose to delay the decision to have a prophylactic mastectomy, but did consent to having a prophylactic hysterectomy.

Hallowell (1998) reported that some of the participants in her study considered that prophylactic surgery was unacceptable, rationalising their decision in terms of the absence of illness or disease. This suggestion is similar to my earlier discussion of the health-illness continuum and how perceptions may vary between individuals. Moreover, it also draws upon the 'elective' nature of any risk-reducing surgical procedure:

386 Jade: And it's preventative surgery as well, isn't it, so it's not like
387 you're having surgery because there is something wrong. I
388 think, there is that part of it to get round.

Jade, interview, lines 386-388.

Jade constructed her account so that it functioned to both defend her decision not to pursue surgery, whilst simultaneously enabling her to be perceived as responsible. She argued, "it's not like you're having surgery because there is something wrong" (lines 386-7). Again, women's perceptions of the disparity between the states of health and disease, and their association with elective or essential surgery, are emphasised. Jade's account demonstrates that although she recognises that she is at-risk, she believes that this is not the same as being diagnosed with cancer. Consequently, any surgery she may have would be preventative and not "because there is something wrong" (line 387).

Women also rationalised their decision to delay surgery in relation to their age and marital status. Whilst the majority of my sample were married and had children, Jen was neither married nor living with a partner. When I asked her if she had made any decisions regarding how to manage her risk surgically, she replied stating:

70 Jen: Not as yet, because **I've just gotten divorced** and I've got a
71 four and a six year old, so it's very difficult.
72 Emma: Do you have any strong feelings about the options that you were
73 given?
74 Jen: It's major isn't it. It's not just physical, its not just a physical
75 operation, its mentally, and err, **if I was still happily married**
76 **then I would probably have had it done sooner.**

Jen, interview, lines 70-76; emphasis added.

As the data extract reveals, Jen argues that her justification for delaying surgery is her divorce (line 70). This explanation can be read in two ways. Firstly, it could be argued that Jen's account demonstrates how women fear that the aesthetic result of breast cancer surgery may have a negative effect upon their attractiveness to (future) partners. Andrea, a respondent of Saywell et al (2000) is reported to have rationalised her decision to delay surgery because, like Jen, she was single and was worried that a mastectomised woman would be unattractive to men. However, Jen's rationale is also shaped by her concerns about who would care for her children whilst she recovers from surgery. She explained, "I've got a four and a six year old, so it's very difficult" (lines 70-71). Both of these explanations are reinforced with Jen's assertion that, "if I was happily married then I would probably have had it done sooner" (lines 75-76). Later in the interview whilst discussing the differences between the decision to have a mastectomy or an oophorectomy, Jen returned to justification of how her divorce had influenced her decision-making:

170 Jen: Ovaries doesn't seem to bother me. Breast does. Ovaries, it's
171 more difficult now, 'cos beforehand, I have two children and you
172 know, I am happy with both, but what happens if I meet
173 someone that hasn't got any children?

Jen, interview, lines 170-173.

Jen's explanation is designed to emphasise that her decision to delay risk-reducing surgery is altruistic. Should she have an oophorectomy and then meet a partner who wanted to have children, she would not be able to conceive. Her decision to delay surgery is thus depicted as a selfless action, putting the needs of a yet unknown partner before her own, and her own health.

Despite the rationales given for their decisions not to have surgery, both Jen and Jade constructed their accounts in order to give the impression that they intended undergoing risk-reducing surgery at some point in the future. Both women placed a time span upon their decision to delay surgery. Jade commented, "I will definitely have surgery when the time is right" (line 302) and continued to explain that she believed that the 'right time' to make the decision to have surgery would be when she was 35 years old. Jen too felt that she would contemplate having surgery when she was 35 years old[43]. Jen explained:

256 Jen: I give myself a limit. You know, I think 30 is too young for me
257 personally, so I think 35, I'll wait until then and then I will think
258 about it.

Jen, interview, lines 256-258.

The accounts offered by Jen and Jade, whilst defending their decision not to undergo risk-reducing surgery, place an emphasis upon their age. The women argued that they felt too young to contemplate having surgery. Firstly, surgery may be declined because the women feel that they are too young to lose their breasts and their ovaries. Related to this, are the associated concerns regarding how mastectomy may result in the loss of femininity. Secondly, the account is cleverly constructed so that the decision to delay surgical decision-making is defended. By setting a limit upon their delay, until they reach the age of 35, the women are indicating that they are aware that early-onset breast cancer is rare before the age of 35 years old (Berger and Bostwick, 1998). However, other women interviewed did have risk-reducing surgery at a young age. Zoë was 28 years old when she underwent a bilateral prophylactic mastectomy[44]. However, unlike Jen and Jade, at the time of her operation Zoë was married. Thus, it seems that like the decision to have risk-reducing surgery, the decision not to have surgery is also multi-faceted. Marital status, age and the non-essential nature of surgery were all influential factors that women rationalised had affected their decision not to have risk-reducing surgery.

[43] Both Jen and Jade were 28 years old when they participated in the interviews.
[44] Although Caitlin, at 26 years old was the youngest woman I interviewed who had undergone surgery, the procedure was necessitated by the presence of a malignant tumour.

8.5. Consequences of the decisions made.

Bertero suggested, "cancer and cancer treatments are, by their definition, destructive" (2002:356). As I demonstrated in the previous section of the chapter, the decision to either go ahead or delay prophylactic surgery was rationalised in a variety of ways. However, within each account given by the women, attention was paid to the consequences that breast removal would have for them, and as such they mirror Kasper's suggestion that:

> breast loss will significantly alter a woman's femininity, self-esteem, identity, body-image and relationships.
>
> Kasper, 1995:199.

In this section of the chapter I discuss the accounts women gave regarding the consequences and outcomes of their decisions. As I summarised in chapter three, the existing literature is filled with accounts of women's reactions to their breast cancer diagnosis, or news that they are at-risk of breast cancer. Within such papers, it is typical that:

> narratives about breast cancer function [whereby] the illness [is situated] within trajectories of life-events…[and] feminine worth is determined in sexual and maternal terms and threatened by the diseased breast.
>
> Saywell et al, 2000:45.

Much of this existing work has relied upon participants recording their experiences via questionnaire responses. However, pre-defined answers will inevitably be too narrow and restrictive to fully address women's concerns and experiences. For example, van Oostrom et al (2003) utilised three trait scales in order to investigate long-term psychosocial consequences of carrying a mutated BRCA gene. In each of these scales, women were asked to choose a number in a restricted range that signified their response; women could choose between five and 25 when describing their perceptions of their body-image post mastectomy, two and ten for their breast related body-image, and 15 and 17 to describe their general sexual functioning. The scales were designed so that results would reflect the higher the score given, the greater the problem experienced. Results generated showed that, "carriers reported less satisfaction than

non-carriers on the general and on the breast related body-image scales" (van Oostrom et al, 2003:3869) and "more changes in their sexual relationship since genetic test disclosure than non-carriers" (van Oostrom et al, 2003:3870).

Similarly, Metcalfe et al (2004) investigated women's perceptions of their body-image following treatment for breast cancer. They utilised a 53 item questionnaire, which explored women's feelings of vulnerability, body stigma, limitations following surgery, and concerns about their body. However, respondents were asked to match their experiences to one of just five points along a Likert scale. Metcalfe et al's results illustrated, "women's mean distress levels were only slightly above normal values" (2004:22). Whilst they reported that "women who had reconstruction did have higher levels of satisfaction, in terms of body shape and appearance, than those who chose not to have reconstruction…..women reported…the perceived need to keep their body hidden and to avoid physical intimacy" (Metcalfe et al, 2004:2).

Whilst Metcalfe et al's (2004) and van Oostrom et al's (2003) studies discuss the impact that prophylactic surgery can have upon a woman, they fail to examine the actual accounts of the women they write about. Utilising in-depth qualitative interview data allows a greater understanding of the experiences of women at-risk of HBOC. Moreover, whilst the accounts collected for this study match the categories outlined by Saywell et al (2000), namely the sexual and maternal breast, they also embrace many of the topics that Metcalfe et al (2004) and van Oostrom et al (2003) investigated.

Earlier in the chapter, I referred to Saywell et al's assertion that "breasts are iconic of both female sexuality and maternity, and as such, are often the currency through which feminine value is attributed" (2000:11). In analysing the consequences of women's decisions to undergo a prophylactic mastectomy, Sacks' (1984) work "on doing 'being ordinary'" is drawn upon. Saywell et al's statement conjectures that to be recognised as a woman, one must have breasts. Hence, having breasts is almost an obligation that allows women to be seen to be 'ordinary'. The following analysis examines the accounts women gave and focuses on how they achieved the action of 'being a woman'. Sacks considered that it is "something [about] the way somebody constitutes [them] self, and in effect, a job that persons and the people around them may be coordinatively engaged in, to achieve that each of them, together, are ordinary people" (1984:415). He

continued, stating “part of the job is that you have to know what anybody / everybody is doing; doing ordinarily” (Sacks, 1984:415). Therefore, in the case of women doing ‘being ordinary’ women, it is how breast cancer or the risk of breast cancer can jeopardise being a woman, which is now turned to.

In discussing their perceptions of the consequences of mastectomy, the women are seeking to be regarded as ordinary. Breast cancer, or the risk of breast cancer, threatens their ordinariness, as:

> breast cancer is especially culturally laden because of the problematic ways in which femininity is located in and value attributed to the female body.
>
> Saywell et al, 2000:39.

Saywell et al’s (2000) summary is consistent with the many descriptions of the breast and its relation to a woman’s femininity that are offered by the existing literature. The field is dominated to such an extent with suggestions that breast loss due to mastectomy has a negative impact upon a woman’s perception of her sexuality and body-image that Wilkinson and Kitzinger described it as, “a major preoccupation of the psychiatric and psychological literature on mastectomy” (1993:230). As I discussed earlier in the chapter, many of the previous studies investigating women’s satisfaction with the outcome of surgery have relied upon the use of trait scales, whereby statistical measurements are used to capture an understanding of women’s experiences. These studies have concluded that women experience little ‘impairment’ when comparing their perceptions of their body-image before and following surgery (van Oostrom et al, 2003; Metcalfe et al, 2004). However, existing qualitative work suggests otherwise (Hopwood et al, 2000; Bebbington Hatcher et al, 2001). As the following discussion illustrates, women were concerned with the aesthetic appearance of their breasts following mastectomy, and were concerned that their breasted or non-breasted, appearance would look abnormal. Wilkinson and Kitzinger (1993) argued that:

> the message for a woman who has just had a mastectomy is that her body is now defective, and that her first priority will be to seek an artificial cosmetic remedy.
>
> Wilkinson and Kitzinger, 1993:231.

All of the women in this study who underwent breast surgery had breast reconstruction. Although writing about cosmetic enhancement for non-medical reasons, Davis (1997) argued that it should be recognised that for some women undergoing reconstructive surgery was:

> an understandable and unavoidable course of action…..not because their bodies were not beautiful, but because they were not ordinary – 'just like everyone else'.
>
> Davis, 1997:169.

Little maintained that cosmetic, or reconstructive surgery, "gratifies a patient's desire to meet the norm" (1993:172). Thus, "what appears at first glance to be instances of choice turn out to be instances of conformity" (Morgan, 2003:172). Hence, in 'choosing' to have reconstruction, women are conforming to social expectations related to what a woman should look like, and thus in Sacks' (1984) terms, are doing 'being ordinary'. A recurring theme throughout this section of the chapter is women's concerns with their appearance following mastectomy; would, or did they look normal, or abnormal?

Caitlin's desire to have implants, and thus have her appearance return to some semblance of normality, conflicted with the opinion of her surgeon. She explained:

130	Caitlin:	At the time, I think, when they did do this, Doctor B
131		at the time really didn't even want to consider putting implants
132		in said he just wanted to take the breasts off and get rid
133		of the cancer and that was it, and I said no, I'm too young
134		to have just a mastectomy, you know, I do not want that,
135		I really really do want implants.

Caitlin, interview, lines 130-135.

The account Caitlin gave demonstrates the different stances of the doctor and the patient. In wanting to leave her breasts unreconstructed, Caitlin's surgeon was demonstrating that he was aware of the problems that could develop should she have implants[45]. In justifying her decision to act against medical advice, Caitlin drew

[45] As I demonstrated in chapter one, even if a woman has a total mastectomy, there is a possibility that cancer will develop in the remaining breast tissue. However, it is more difficult to pick up abnormalities in mammography screening when the woman has implants (Berger and Bostwick, 1998). Moreover, there are problems associated with breast implants that can have an iatrogenic effect upon the patient's health. Implants may be carcinogenic themselves (Love, 1990). Although silicone implants are no longer used, it

attention to her age, stating, “I’m too young to just have a mastectomy” (line 133-134). She was 26 years old when she had her mastectomy. By accentuating her age, Caitlin is reinforcing the notion that whilst it is important for women to look and feel normal, it is even more significant when younger women undergo a mastectomy that they feel and look normal, and that they appear to be an ‘ordinary’ woman.

Despite reconstruction offering the chance for the women to feel that she looks ‘normal’, it does not always have the desired outcome. Davis asserted, “the patient may simply find that the surgery does not bring the relief that she had expected” (1993:26). Before deciding to undergo risk-reducing surgery and reconstruction, women attending the clinic were shown photographs of similar surgical examples so that they were aware of what to expect. However, some of the women described that they felt quite shocked at these images. Laura commented:

1 Laura: I was quite horrified by the photographs to be honest. And I
2 can remember Nurse H saying ‘what’s wrong?’ and again, very naïve,
3 I’d got it into my head that I’d just look like, err, if I had it done for
4 cosmetic reasons, that I’d just look like that, which is really naïve
5 if you think about it because there’s got to be scars there.

Laura, interview, 32.00-32.21 minutes.

Before undergoing surgery Laura was under the impression that the procedure would have the same aesthetic outcome as cosmetic breast augmentation. However, viewing the photos had altered her perception of the outcome and understanding of the procedure that she would have. She describes how she felt naïve when she realised that the two operations were different (line 2), and horrified by the aesthetic result (line 1). When describing her reaction to seeing the photographs, Jill, like Laura, was unimpressed with the aesthetic outcome of reconstruction following prophylactic surgery. She stated:

remains to be seen if saline filled implants will also have a negative effect upon the patients’ bodies.

60 Jill: They've shown me this booklet, which they show you the ones
61 that they've done and they were really pleased with themselves
62 and you know, I have to say I wasn't, they didn't really impress
63 me. Not because they looked awful or anything but its not like
64 going in and having a boob job and having them lifted and so
65 on so they look more wonderful than they did before.

Jill, interview, lines 60-65.

Jill's account demonstrates a further difference in the opinions of the doctors and the patients regarding the risk experience. Jill comments that whilst "they [the doctors] were really pleased with themselves" (line 61-62), she was not impressed by the reconstruction pictures. Unlike Laura however, who considered the pictures to be horrific, Jill explained that the pictures did not "look awful or anything" (line 63). Rather, she found that the pictures contested her vision that her reconstructed breasts would be an improvement upon their current state.

The accounts given by both Laura and Jill demonstrate that women may be under the mistaken impression that reconstruction will result in an improved, augmented version of their breasts. This assumption highlights a further problem, or misunderstanding related to whether prophylactic surgery is considered to be essential and medically required, or elective. Women with breast cancer would rarely describe how they hoped that their breasts would "look more wonderful that they did before" (Jill, line 65), as if they had undergone a breast augmentation. Therefore, why do some women who have had, or are considering having a prophylactic mastectomy to reduce their risk of developing cancer?

The procedures involved in performing a mastectomy or a breast augmentation are dissimilar from one another. Augmentation adds to the existing tissue with the use of implants, and leaves only minute scars. By contrast, mastectomy removes breast tissue and involves heavy scarring of the chest. Reconstruction can take the form of chest expanders and small saline implants which are then filled over a period of six months, or by the invasive TRAM flap procedure (see images on pages 207-208).

The accounts given by Jill and Laura demonstrate that women may not adequately comprehend that their operation is carried out first and foremost to remove cancerous,

or risky breast tissue, and will not result in a perfect aesthetic outcome. For some women, this misconception had devastating consequences. Zoë explained that she had subsequently undergone psychological counselling because:

156 Zoë: They didn't tell me that when I had the operation that I'd wake
157 up with nothing, you know, just flat-chested, I presumed, you
158 know, I assumed that I was going down with a pair of boobs
159 and I was going to come back with a pair of boobs, you know
160 so mentally, it did my head in, 'cos the first thing, as soon as
161 you wake up, you think 'look what they've done', I mean you're
162 still groggy and you don't know what you're on about, but
163 you want to look, and I can remember looking down at it and
164 thinking that they had done the completely wrong operation,
165 they took them away and that's it, what am I going to do?

Zoë, interview, lines 156-165.

Zoë's account reveals a further misunderstanding concerning what women understand about the prophylactic procedure that they will undergo. As the extract demonstrates, Zoë assumed that she would return from theatre with a pair of breasts to replace those that she had removed. She describes feeling shaken and traumatised, commenting, "mentally, it did my head in" (line 160) when she saw that she was flat-chested.

Undergoing a mastectomy may also result in nipple loss. When breast tissue is removed, the areola becomes disconnected from its blood supply and nerve endings. If left in situ, there is a danger that the nipple will necrotise and fall off. Consequently, some surgeons advocate that the nipples are removed during surgery.

The possibility that women could lose their nipples and the subsequent psychological and bodily effect that this may have upon them, is rarely addressed in the existing literature. When it is discussed, it is only in the form of one of many side effects of mastectomy (see for example, Bebbington Hatcher and Fallowfield, 2003). Because of this lack of debate, prior to my fieldwork, I had not considered the loss of nipples and how this might affect women or influence their decision-making. However, during my first interview, Zoë spoke about her surgery and period of recovery. In the course of this, she recalled her fears that she might lose her nipples:

504 Zoë: So I'm in the bath, and Amy [daughter] is washing my hair…
507 ……she looked down and she went (gasps),
508 'Mum, your nipple', and I went 'what?' and thought, I can't look,
509 I said 'what?' and she said 'it's hanging off', I looked down and it
510 was just hanging half and I thought oh my god, and she's going
511 'I'm ringing me Nana, ringing me Nan', so me Mum came round
512 and I was sat in the bath, daren't look, me Mum came running
513 round and she said 'let me look let me look' and I'm sat there
514 saying 'I can't believe it after all this time I'm going to lose my
515 nipple'. She looked, and she said 'you know what, all it was,
516 was the iodine and the blood (laughs) had dried and been
517 washed off'. Well, I didn't know, and I couldn't bring myself to
518 look and I didn't want Amy to keep looking, you know, I'd been
519 keeping her out of the bathroom after she'd rung me Mum,
520 and I said 'right stay out there, you don't need to see this,
521 it's not nice'. Me Mum came in and told me, and we sat in the
522 bathroom and we cried with laughter, but it was the shock, but I
523 just sat like that and thought, I can't look, I can't do it.

Zoë, interview, lines 504-523.

Although Zoë's surgeon had been able to save her nipples, she knew there was a possibility that the nipples might subsequently necrotise. Her account, although recounted humorously during the interview, illustrates her profound underlying fear that she would lose her nipples. Other women also found even the possibility of losing their nipples to be traumatic. For Jill, the prospect that she could lose her nipples was used as a justification to decline surgery. She explained:

278 Jill: I've got this fear of not having my own nipples, and having to
279 wear these horrible silicone ones which I really don't want to.
280 I think if someone could say Jill, I guarantee you know, you'll
281 be able to keep all of your own skin.

Jill, interview, lines 278-281.

Although no one would force Jill to wear the "horrible silicone" prosthetic nipples (line 279), Jill constructs her account, and one of her justifications for declining surgery, to reflect her opinion that she would have no other alternative but to wear them. Rather than recognising them to be an option intended to help woman appear and feel normal following mastectomy, Jill perceived the silicone nipples to be a requirement. Moreover, her explanation implies that she cannot, and is unwilling to consider

replacing her own nipples with synthetic ones. Consequently, the account emphasises her resistance to the procedure.

Like Jill and Zoë, Trisha was alarmed about losing her nipples. However, she rationalised the loss of her nipples in relation to the outcome being the best way that she could lessen her risk of developing breast cancer. She explained:

312 Trisha: I wasn't too bothered about losing the breast, but I was about
313 losing the nipples and really didn't think that I could handle that,
314 but I found that I've got to, so I feel a bit weird, but I could have
315 lost them for a totally different reason, so, you know, there is
316 every reason to get upset about it, but not devastated about it,
317 because you know, you go through all the trauma of having the
318 surgery done and you're still leaving a little bit there, you know,
319 closing the door, locking the door, but leaving the key in, and it's
320 like that made me think mmm, you know, maybe they've got to
321 Go

Trisha, interview, lines 312-321.

Trisha's account reflects her opinion that the reality of being at-risk of HBOC and taking all possible measures to reduce the threat was more important to her than losing her nipples. She comments, "you're still leaving a little bit there, you know, closing the door, locking the door, but leaving the key in, and it's like that made me think, mmm, you know, maybe they've got to go" (lines 318-321). The comparison that Trisha makes, equating the protection of her health with the protection of her home is interesting. Her account is constructed in such a way that it makes women who chose to keep their nipples appear negligent. Saywell et al argued, "allusions to vanity are situated in a moral framework and posited implicitly as irresponsible and irrational" (2000:47). Trisha's account succeeds in suggesting that keeping one's nipples despite the related risk of developing breast cancer, when you have already made the decision to have a mastectomy is illogical, irresponsible and irrational.

As this discussion has shown, women were fearful of losing their nipples and perceived their loss to be devastating. That the women found the loss of their nipples to be more significance than the loss of their breasts is interesting and surprising. I asked Zoë why it was important that she kept her nipples:

526 Zoë: For my femininity … because I think that they look normal.
527 You want, if you're gonna do it, you want to look as normal as
528 possible.

Zoë, interview, lines 526-528.

Women feared the loss of their nipples because they perceived them to be a symbol of normalcy and ordinariness. Whatever size or shape their breasts, everyone has nipples. Without having nipples, women feared that they would look and feel abnormal, and different to other people who had not undergone a mastectomy. Within the vast normal range of breast sizes and shapes, a breast that has had its tissue removed might still pass as a 'normal' breast. However, the potential for being perceived as 'normal' is less if the nipple has been removed. Thus, in recounting their fears of losing their nipples, the women were demonstrating that they wanted to be seen as an 'ordinary' woman.

The notion of normality was also touched upon when women described their decision about what size their breast reconstruction would be. Laura recounted what she told her surgeon:

1 Laura: I said 'I don't want to be really big', and with the expanders, they're
2 very in your face, very up here [motions to breast bone], very big and
3 I felt very self conscious of them, and I said to him 'I just want little
4 and natural ones', you know, you could have something really
5 cosmetic, what women would pay to have done, but I didn't. I said I
6 just wanted to disappear into the background and I don't want people
7 going 'oh she looks really nice 'cos she's had all this done'. I just
8 wanted to fade into insignificance really.

Laura, interview, 32.50-33.40 minutes.

Laura's account provides an additional example illustrating how women react to prophylactic surgery as different to elective, cosmetic augmentation. Laura wanted her appearance to look natural not enhanced. Her comment "I just want little and natural ones" (lines 3-4), echoes Hallowell's (2000) suggestion that women wanted to look as 'natural' as possible following reconstruction. Women's accounts stress their opinion that the reconstructive surgery they had was distinct from cosmetic enhancement. Laura explained that she could have chosen to "have something really cosmetic, what women would pay to have done" (lines 4-5), but that she wanted to fade into "insignificance" (line 8), and thus not stand out or draw attention to herself.

Implicit within their accounts was the suggestion that women found it insulting that their prophylactic mastectomies and reconstructions were mistaken for cosmetic augmentation. They explained that they did not want others to misconstrue the reason that they underwent surgery. Rather, the women wanted recognition that they had suffered, and that they had had surgery because of the presence or risk of disease, not because they chose to have breast implants. Laura explained "I don't want people going 'oh she looks really nice 'cos she's had all this done'" (lines 6-7). Likewise, Zoë stated:

733 Zoë: The staff at work, at the pub, they were all having bets about
734 how much I had paid for them, you know, so one day, we
735 were all sat having a drink and I said, 'right girls, this is what's
736 happened'.

Zoë, interview, lines 733-736.

Zoë and Laura both defended their decision to undergo reconstruction from claims that they may have undergone cosmetic breast augmentation. Zoë explained that she felt she had to inform people about her surgical decision-making, because they had been "having bets about how much I had paid for them" (lines 733-734). Zoë's account implies that she felt that by assuming that she had had cosmetic surgery, others would belittle her risk of HBOC and the decisions she made because of it. Consequently, she felt that she had to justify her decisions to others, and demonstrate that she was acting responsibly by reducing her risk, rather than having surgery to enhance her breasts.

The accounts of decision-making that have been discussed throughout this thesis have emphasised that women constructed their utterances so that it would be recognised that they justified their decisions regarding genetic testing and risk-reducing surgery in terms of the obligations inherent in being a mother. However, whilst discussing the implications of their surgical decision-making, the women who chose to undergo surgery did not mention how mastectomy or oophorectomy would have a negative effect upon their role as a mother.

Rycroft claimed that "the breast…..is synonymous with 'the mother" (cited in Yalom 1997:147). Both literature and art depict the breast as a life-giver (Yalom, 1997). Frequently, paintings portray the nursing mother with the baby suckling at her breast, and, "in stories about prophylactic mastectomy, the maternal status of subjects is often

emphasized" (Saywell et al, 2000:48). Undergoing risk-reducing mastectomy would remove the opportunity for a woman to breast-feed her child. Thus, for women undergoing a prophylactic mastectomy, an activity that symbolises women's ordinariness, breast-feeding, is unattainable.

Although Joanna had declined to undergo genetic testing and thus was not required to reach a decision about undergoing surgery, she commented that she would, "be sad to miss out on the breast-feeding" (Joanna, interview, line 410). However, none of the other women spoke about breast-feeding.

The majority of the women I spoke to had children, and a minority indicated that they would like to have more. Whilst they discussed this in relation to the pressure to conceive before their ovaries would be removed, they did not mention how breast removal might affect their experience of motherhood. When I interviewed Zoë, she was five months pregnant. Despite her pregnancy, she did not discuss how her mastectomy would alter her experience of motherhood. However, she did mention that if she chose to have another child, she'd "have another one straight away and then I will go in and say, look just take them [ovaries] out now" (lines 703-705), before her risk of developing ovarian cancer became even greater.

The omission of any detailed discussion within my data of how breast loss would affect motherhood is one example of how this study has altered from the existing studies. I am not suggesting that women's concerns regarding the loss of the maternal breast have been over-emphasised. Rather, the lack of discussion here demonstrates that the fluid interview structure utilised enabled the women to talk about what was important to them, at the time of the interview. Clearly, for the women I interviewed, other factors were more significant whilst recounting their experiencing of being at-risk of HBOC and the decisions they made.

Lastly, the existing descriptions of womanhood emphasise the sexual breast. Thus, it would be expected that women's accounts would demonstrate their anxiety about how breast loss would affect their sexual relationships. Hallowell reported that the women involved in her study, "worried that having a mastectomy would [have] a negative effect upon sexual relationships as they believed that they would appear less attractive to their

sexual partners following the operation" (1998:271). Similarly, Kasper (1995) offered the following quotation from a respondent named Connie:

> I don't think I would ever marry again because I wouldn't wish this on another man, to accept a woman who has lost two breasts.
>
> Connie, cited in Kasper, 1995:206.

Connie's account depicts a woman who has lost two breasts as "sexually damaged goods" (Hobler Kahane 1995:2), who would be unattractive to another man. As discussed earlier in the chapter, Jen's account of her decision to delay having surgery can be interpreted as similar to that offered by Connie. Jen implied that her status as a divorcee, who has to meet new partners, influenced the choice that she made.

Other women that I spoke to voiced their concerns regarding how having surgery resulted in negative outcomes for the sexual breast. Many of the women feared that their decision to undergo risk-reducing mastectomies might harm their marriages and sexual relationships with their partners. Jill commented that one of the influences upon her decision to delay having a mastectomy was that because "[her] husband [was] quite a breast man" (line 302). Here, Jill constructs her rationale so that the decision to delay surgery and not take-up all available risk-reducing measures is seen in relation to her wish to keep her husband happy. She feared that despite his assurances otherwise, he would find her post-mastectomy body unattractive. By giving this account, Jill is attempting to apportion or share the blame for her decision not to have breast surgery with a third party, her husband. Moreover, she is creating the impression that she wants to appear like a 'normal' wife, or an ordinary woman. Like Jen's account of her decision to delay having an oophorectomy, Jill is also constructing an image of herself as acting altruistically, even though her decision might place her health in jeopardy. Hallowell wrote of women wanting to "appear natural in the eyes of others, particularly their sexual partners" (2000:176). Zoë feared the reaction that her new partner would have the first time he saw her reconstructed, scarred breasts. She described how:

324 Zoë: …..getting
325 undressed in front of a new partner for the first time, was like ‘oh
326 my god, what am I gonna do?’

Zoë, interview, lines 324-326.

Zoë’s account illustrates that she felt as if her mastectomy had made her sexually unattractive. Her explanation lends itself to the assumption that she felt ashamed or embarrassed by her scar, or that the treatment she had received may be stigmatised. Moreover, Zoë’s description also indicates that women fear that they will look abnormal following mastectomy, and supports Hallowell’s (2000) argument.

Published accounts of women’s post-mastectomy experiences discuss the effect that the procedure can have upon sexual relations (Hallowell, 2000; Hopwood et al, 2000). Prouser (2000) described her own breast cancer experience, and recalled:

> one of my worst fears…was what this loss would mean for our sex life.

Prouser, 2000:156.

Following her mastectomy, Caitlin felt that her sex life had altered. She explained:

515 Caitlin: I suppose the only other thing that does change is,
516 erm, the way that I feel in that respects, is sex. It’s not so, I just
517 don’t, even though me and my husband still do, I can’t bear him
518 going near my boobs at all.

Caitlin, interview, lines 515-518.

Caitlin is not alone when she describes her unwillingness for her breasts to be touched. Bebbington Hatcher and Fallowfield claimed that most women participating in their research did not “wish their breasts to be touched” following their mastectomy (2003:4). Although Caitlin does not offer any clarification of why she does not want her breasts to be touched, several reasons could justify her explanation.

Following a mastectomy, a woman may no longer associate her reconstructed breasts as sexual objects; they are a reminder of her missing breast tissue and of her breast cancer diagnosis. Moreover, she may feel embarrassed, or ashamed of her appearance, and her

breasts may feel physically different compared to their pre-surgical state. They may be painful to touch or have touched. She may believe that because of the surgery, she has been disfigured and will be unattractive to her husband.

8.6. Regretting the decision to delay surgery?

Earlier in the chapter I discussed how some women chose not to have any risk-reducing surgery, whilst others opted to only have a hysterectomy. A consequence of patient participation in decision-making is that the individual has to take responsibility for the choice made and any consequences of it. Kunkel et al claimed, "women who play a more active role…in decision-making now shoulder an increased burden of responsibility for making the right choices" (2002:130). Whilst the women participating in this study reported that they were presently satisfied with the decisions they had made, some did query whether they would regret not undergoing surgery in the future. Moreover, they questioned whether the decision they considered was the right one when they made it, would continue to be so. For example, Judy explained:

1 Judy: I think I'm pretty satisfied with what I've done so far, but
2 saying that, if I develop a lump, will I regret not having
3 them [breasts] off? Who knows?

Judy, interview, 22.03-22.30 minutes.

Although Judy's account emphasises her current contentment with her decision to decline the offer of a prophylactic mastectomy, the language she uses does not convey her whole-hearted satisfaction. Although she explained, "I'm pretty satisfied with what I've done" (line 1), she is unsure of whether she will be as satisfied with her decision should she develop breast cancer in the future, commenting, "who knows?" (line 3). Jen also questioned whether she would remain contented with her decision not to have surgery, but unlike Judy, appeared to have given it more consideration, and provided a lengthier account. She stated:

250	Jen:	I'd be annoyed with myself if I got it
251		and I'd be thinking, oh you know, ten years ago I could have
252		had this done and it would have prevented all this and now
253		I've got to have them [breasts] removed anyway and I've got to
254		have chemo[therapy] and radio[therapy] and I've had cancer.

Jen, interview, lines 250-254.

Whilst Judy questioned whether she would still be content with her decision, stating, "who knows" (line 3), Jen explained that she'd be annoyed with herself (line 250). She uses her account to emphasise that she could have taken steps to prevent cancer, and although she chose not to lose her breasts, that she would have to anyway should she develop cancer. Jen's explanation mirrors Cassie's rationale (page 214) that she felt like she had no option but to have surgery, because otherwise she would be to blame if cancer did develop.

8.7. An 'exceptional' threat?

Potts argued that the important ideological discourse that influences women's understanding and meanings of breast cancer has been shaped by "constructions of embodied femininity [that] impact both individually and collectively on women and significantly shape the cultural valorisation of reconstruction, or the re-normalisation of the visible female body" (2000:8; emphasis added). I have analysed the accounts given by the women in terms of how they constructed how they were doing 'being' a woman, or 'being ordinary', the women themselves chose to present and discuss information about their at-risk experience that they felt was significant and important. Consequently, they demonstrated how they themselves have been influenced by the social construction of femininity and womanhood that Potts criticised.

Lorde commented, "breast cancer and mastectomy are not unique experiences, but ones shared by thousands of …women. Each of these women has a particular voice to be raised in what must become a female outcry against all preventable cancers, as well as against the secret fears that allow those cancers to flourish" (1996:3). Each of the women participating in the interviews chose to talk about their 'breasted experience' (Young, 2003), and in doing so, responded to Lorde's cri-de-cœur that each woman has a voice to be heard in regards to breast cancer. The accounts analysed throughout this

thesis were women's own recollections of their own breast cancer experience and Potts' (2000) assertion seems overly critical in parts. Whilst it should be acknowledged that the women are likely to have been influenced by societal expectations – which is something we are all guilty of, to suggest that women are overwhelmed by these expectations, is to argue that they are "cultural dopes" who have no opinion of their own (Garfinkel,1996:68). Rather, given the real significance within the accounts given that the impact that the loss of their breasts and the effect that this would have upon their quality of life, it seems too clear-cut to accept the theory of the social construction of women's identity and not look beyond to the actual lived experiences of these women.

The accounts examined in this chapter have been similar in content to those published previously, which describe the impact that mastectomy and oophorectomy can have upon the body-image of women with breast and ovarian cancer. Consequently, I conclude that the rationales for the decisions made, and consequences of undergoing prophylactic surgery are 'unexceptional'. The fears and anxieties that women reported are consistent with those of women who face surgery because they have been diagnosed with cancer.

Conclusion.

> Genetics is currently the undisputed king of the biological disciplines. So rapid are the advances in this field, and so ubiquitous their impact, that it has been said that we are living in the midst of a 'genetic revolution'.
>
> Caulfield, 2000:439.

Recent developments in genetic medicine, following the successful completion of the human genome map, have purportedly heralded a revolution in medicine and health care that has led to the "dawn of the genetic age" (Conrad and Gabe, 1999:505; Lander, 1999; Caulfield, 2000; Reid, 2003). Described as "the greatest intellectual moment in history" (Ridley, 1999:5), it was postulated that the mapping of the human genome and subsequent production of the 'book of life' (Rose, 2004) would "reshap[e] conceptions of health, disease and normality" (Petersen and Bunton, 2002:3). Scientific advances promised interventions against disease such as gene therapy (Russell, 1997), pre-implantation genetic diagnosis, which would enable the creation of 'designer' or 'donor' babies (Lee, 2002), pharmacogenetics, whereby medication could become personalised for the individual (Wolf et al, 2000) and widespread genetic testing for all manner of inherited diseases (Genewatch UK, 2002). However, has the claim that genetic medicine offered a "revolution in health care" (Reid, 2003), as described in the introduction to this thesis, been overemphasised?

In concluding this thesis, I respond to John Reid's (2003) statement, that "we are standing on the threshold of a revolution in health care", in light of the findings of this study. In doing so, return to the research question, "are women's experiences of being at-risk of HBOC genetically exceptional?". Throughout this thesis, I have examined the women's accounts of their HBOC experience in response to the arguments offered by proponents of the genetic exceptionalism thesis. Focusing on the experiences of women at-risk of HBOC, the decisions they made because of this risk and the rationales given for these decisions, I have questioned whether genetic medicine has created the widespread revolution in health care that was envisaged. If such a revolution has occurred, then women's HBOC experiences would be "qualitatively different" from those experienced by women diagnosed with breast or ovarian cancer (Friedman Ross, 2001:145).

Fundamental to the notion of a genetic revolution is the idea that genetic medicine has introduced a novel element into the medical encounter. Advocates of genetic exceptionalism support the idea of a genetic revolution, by arguing that genetic and non-genetic diseases are distinct from one another. Proponents of the genetic exceptionalism thesis consider that genetic information is different from non-genetic information as it is prophetic, acts as a future diary, is stigmatising, and reveals information about biological relatives (Murray, 1997). Given these differences, it could follow that the patient experiences of those diagnosed with genetic and non-genetic diseases will be dissimilar from one another, and that women's experiences of being at-risk of HBOC are therefore exceptional. Moreover, such differences would support the notion of a revolution in health care[46].

In each of the data chapters that precede this conclusion, I have addressed a distinct stage in women's experiences of being at-risk of HBOC. It is the aim of this chapter to draw together the conclusions from each of these four chapters, and respond to my research question and hypothesis. Following this, I will evaluate the thesis, suggest future lines of enquiry developing from this research, and make policy recommendations. Finally, I will respond to John Reid's statement, with which I began this thesis, that a revolution in health care has occurred.

Is the HBOC experience exceptional?

> Genetic information is special because we are inclined to treat it as mysterious, as having exceptional potency or significance, not because it differs in some fundamental way from all other sorts of information about us.
>
> Murray, 1997:71; emphasis added.

In the introduction to the data chapters, I examined the arguments that are offered to both accept and reject the authenticity of the genetic exceptionalism debate. These arguments were based upon the premise that genetic information is predictive, sensitive and can inform about the health of a third party.

[46] This is not the only way that a revolution in health care could be substantiated. Other examples might include a faster diagnosis and a reduction in the waiting times to see a consultant. However, for the purpose of this thesis, a revolution in health care is narrowly defined, focusing only on how the experience of being diagnosed as at-risk of a genetic disease may differ from being diagnosed with a non-genetic disease.

However, in all but one of the data chapters, I have refuted these claims. For example, whilst genetic information is predictive, so too is other health-related information. Moreover, little of this information can provide any steadfast guarantee. Griffiths et al argued that uncertainty is "inherent in the nature of medical evidence" (2005:511). Continuing their argument, they explained, "epidemiology tells us that smoking is a risk factor for heart attack, but it does not tell us which individuals will be affected" (2005:511). Similarly, testing BRCA positive is a risk factor for developing cancer, but does not tell us which individual will develop HBOC, when the disease might manifest, or whether it will present as breast cancer, ovarian cancer or maybe even both. Consequently, the argument that the predictive nature of genetic information enables the experience of women at-risk of HBOC to be considered exceptional is not supported.

Secondly, Murray (1997) argued for the genetic exceptionalism thesis in light of the sensitive nature of genetic information. However, throughout this thesis, I have argued that there are other examples of health-related information that are also sensitive, embarrassing and possibly stigmatising for the patient to admit. For example, admitting to an HIV positive test result, or informing a sexual partner about a sexually transmitted infection are likely to be sensitive, embarrassing or stigmatising situations. Moreover, as I discussed in chapter two, it is not solely hereditary breast cancer that is a sensitive and taboo topic, but breast cancer in general. Consequently, the argument that the sensitive nature of genetic information enables the experience of women at-risk of HBOC to be considered exceptional is not supported.

Lastly, it is proposed that the ability to hold information about a third party's health is an example of genetic exceptionalism. Yet non-genetic health-related information can be held about another person. I have already discussed the sensitive nature of disclosing information about a sexually transmitted infection diagnosis, but such a scenario also informs us about the health of a third party. However, such an example can only describe the spread of an infectious disease, which is passed along a horizontal line of transmission. The vertical line of HBOC inheritance, in which health-related information can be inferred about a person's extended family, is considered to be an example of genetic exceptionalism.

Despite this last acknowledgment that certain aspects of the genetic experience are exceptional, it is relatively easy to find examples to dismiss Murray's (1997) suggestion of genetic exceptionalism. Therefore, I propose to test the genetic exceptionalism thesis through an examination of my hypothesis, in light of the three thematic outcomes of this study:

i) the medical management of the healthy
ii) the doctor and the patient
iii) the consequences of being at-risk of HBOC

In each of the following sections, I will respond to the hypothesis that **genetic medicine and the knowledge that it produces, is somehow special, unique or different from routine, non-genetic, everyday medical encounters and the knowledge resulting from such consultations.** If the hypothesis is either wholly supported or rejected by each of the three following examinations, then it follows that genetic medicine either has or has not created a revolution in health care.

i. Medical management of the 'healthy'.

A central issue relating to whether women's HBOC experiences can be considered exceptional, and in turn, whether there is evidence from these to support a revolution in health care, is being asked to make a decision that will result in medical intervention when you are currently well.

The rise of surveillance medicine, public health and health promotion has enabled the medical gaze to fall upon the healthy (Armstrong, 1995), with healthy members of the population now comprising the new category of diseased and unwell patients. Jonsen considered, "persons could be designated patients in an anticipatory sense…….persons will become patients before their time. They will be described in disease terms, but 'feel fine' and 'be fine' for years, perhaps always" (1996:8-9; emphasis added). However, although falling under the medical gaze when you have no clinical signs of illness is unusual, it is becoming a more frequent occurrence because of the medicalisation of lives.

Many forms of non-genetic intervention in the lives of the well are made: vaccination and immunisation, surveillance of child development, fertility management and annual health screening. Moreover, as I discussed in chapter two, the medicalisation of childbirth has provided a non-genetic example of how healthy women have their lives medically managed. An extension of this can be seen with the medical management of HBOC. Surgical techniques to manage HBOC risk mirror those utilised to treat women diagnosed with breast or ovarian cancer: mastectomy or oophorectomy. Furthermore, women undergoing surgery at Hospital X are placed on the same ward as symptomatic patients, and are treated by the same clinical team. Women at-risk of HBOC are treated as if they have cancer.

Given the similarities with the medical management of the healthy (as experienced by women in labour, children undergoing vaccination and women facing fertility treatment), can being treated as a patient, when you "feel fine" (Jonsen, 1996:9) as women at-risk of HBOC are likely to be, constitute evidence for a revolution in health care or a genetically exceptional event? Such parallels enable the hypothesis, that genetic medicine and the knowledge that it produces, is somehow special, unique or different from routine, non-genetic, everyday medical encounters and the knowledge resulting from such consultations, to be refuted. A healthy woman, albeit one who is at-risk of developing a disease, falling under the medical gaze cannot be considered either as genetically exceptional, or as evidence of a revolution in health care.

ii. The doctor and the patient.

The second issue relating to whether women's HBOC experiences can be considered exceptional, and in turn, whether there is evidence from these to support a revolution in health care, is the challenge that genetic medicine presents to the doctor-patient relationship.

By definition, a hereditary disease is likely to affect more than just one person. Moreover, it is likely that many of these individuals will be asymptomatic at the time of the consultation. Therefore, the doctor-patient relationship will be challenged, and will require some modification in order to address the difficulties that it will face. Using interactional data derived from a genetic counselling consultation, I analysed how each

party constructed their claim to the ownership of, or occupancy in the patient role within the medical encounter. I argued that there is no longer one patient, illustrating a move away from the sole occupancy of the patient role.

However, the difficulties in establishing the ownership of the patient role, and who should be the main focus of the line of medical enquiry can also be shown in other examples of medical interaction. Sexually transmitted infections and infectious transmissible diseases all implicate others in addition to the person initially treated by the doctor. Yet, such infectious diseases depend upon a horizontal line of transmission. The hereditary nature of genetic disease enables the multiple occupancy of the patient role without exposure to the infection or virus that leads people to seek medical help. It therefore seems that the inclusion of more than one patient in the consultation because of an inherited risk, does provide an example of genetic exceptionalism.

A further challenge to medical interaction is that patients do not need to be symptomatic, as the medical gaze now falls on the "asymptomatically ill" (Novas and Rose, 2000:496). Given these developments, one might have expected the women to report that they had experienced a different style of doctor-patient relationship to that discussed over many years in the medical sociological literature. Nevertheless, women's accounts of their doctor-patient relationship had many similarities with the models that I reviewed in chapter three.

Despite these similarities, no single model can adequately account for what was reported to have happened in all of the consultations all of the time. I therefore reached the conclusion that it is problematic to subscribe to any one model whilst describing the doctor-patient relationship. Consequently, I proposed that re-conceptualisation of doctor-patient interaction is required, taking into account elements from all of the existing models. The currently popular typifications, the disease-centred model, the patient-centred model and the collaborative model, are unable to adequately describe the format of all medical encounters, all of the time. I suggested therefore that any model of medical interaction should be able to incorporate characteristics from each of the existing models. The static models frequently described, are too rigid to represent the fluid dynamics of doctor-patient interaction.

It is important for any model of doctor-patient relationship to be able to react and alter to meet the needs of all parties within the consultation. To illustrate this, I discussed how women reported that they felt as if doctors objectified them by using a disease-centred model of medical inquiry. Barry et al argued, "in the consultation, the patient is most commonly constructed as a purely 'biomedical' entity – that is, a person with disconnected bodily symptoms, wanting a label for what is wrong and a prescription to put it right" (2000:1250). Similarly, the women in this study reported that the biomedical, or disease-centred stance of doctors ignored their holistic needs. Moreover, such a stance allowed the doctors to dismiss their psychological and emotional concerns and anxieties, and merely focus objectively upon their breasts or ovaries as sites of medical intervention.

The need to re-conceptualise medical sociological models of the doctor-patient relationship is not only applicable to genetic consultations. The development of 21st century medical care, reflected in the increase in patient-centred medicine, consumer power and the move away from a disease-centred model of care, has transformed the doctor-patient relationship across the medical sphere (Bensing et al, 1999; van Dam et al, 2003; van Dulmen, 2003).

I have suggested that both the need for a re-conceptualisation of the doctor-patient relationship and the difficulty in establishing who the patient is, have created challenges for medical practice to overcome. Whilst most encounters feature a sole person inhabiting the patient role, more frequently, third parties, such as family members, are becoming implicated[47]. Medical professionals and patients must react to this change. However, the key difference between these cases and genetic consultations is the vertical line of hereditary transmission. Given this difference, I have reached the conclusion that the difficulty of identifying the patient in the genetics consultation is genetically exceptional. My hypothesis states, genetic medicine and the knowledge that it produces, is somehow special, unique or different from routine, non-genetic, everyday medical encounters and the knowledge resulting from such consultations. The vertical line of disease transmission has created a unique difficulty in identifying a sole inhabitant of the patient role. Moreover, the implications of this vertical line of

[47] When the consultation involves a child or a young adult, a third party is always present.

transmission are different from those experienced in non-genetic consultations. The need for an up-to-date model of doctor-patient interaction is not however, a further example of genetic exceptionalism. The demands that contemporary patients make of health care have altered, and sociological models of medical practice should reflect this.

iii. The consequences of being at-risk of HBOC.

A last example of whether women's HBOC experiences can be considered exceptional focuses upon the consequences of being at-risk.

It is possible to test the hypothesis in relation to the rationales that women gave in regard to their decisions to undergo (or decline) genetic testing and risk reducing surgery. Only one woman declined to undergo genetic testing. She justified her decision in relation to her perception that the disadvantages of testing outweighed the advantages. Comparably, the women who chose to undergo genetic testing rationalised their decision in relation to wanting to resolve their anxieties regarding whether they were at-risk, the responsibility that they perceived they had to family members, and the devastating effect of watching a loved one die from the disease and wanting to prevent others from experiencing this.

Women's health and their reaction to both illness and risk were shaped by their responsibilities and obligations to children, parents and spouses. The most prominent influence upon women's decision-making to undergo genetic testing was having children, followed by watching loved ones die from breast or ovarian cancer. Interestingly, Joanna, who declined the offer of genetic testing, had not experienced a close blood relative dying of early-onset cancer. Therefore, from the accounts that women gave to explain their decision-making, I suggest that the care and well being of others came before their own health. Such a finding mirrors much of the early medical sociological work on women's health and health service usage. Novas and Rose (2000) argued:

> when an illness or a pathology is thought of as genetic, it is no longer an individual matter. It has become familial, a matter both of family histories and potential family futures. In this way, genetic thought induces 'genetic responsibility' – it shapes prudence and obligation, in relation to getting married, having children, pursuing a career and organising one's financial affairs.
>
> Novas and Rose, 2000:457.

Graham (1979) reported that women considered that their children's health was often more important than their own, and consequently Novas and Rose's statement regarding "genetic responsibility" (2000:457) builds upon the foundations offered in much earlier medical sociological work. Consequently, I have concluded that the influences upon their decision-making that women reported were not unique to being at-risk of genetically inherited diseases, and as such dismissed the hypothesis

Following the examination of the accounts given to justify their genetic testing decisions, I discussed women's accounts of their surgical decision-making. I drew upon women's perceptions of their body-image, sexuality and feelings of femininity following prophylactic bilateral mastectomy, elective breast reconstruction, prophylactic oophorectomy or prophylactic hysterectomy. I argued that prophylactic surgery, whilst different from essential surgery performed to remove a malignant tumour, was also different from cosmetic or elective surgery. Whilst women were not diseased, their accounts also emphasised that they were not acting for reasons of vanity. They described how they chose to undergo prophylactic surgery because they believed it offered them the best chance of survival. Accordingly, women at-risk of HBOC provided similar rationales to those given by the women with breast cancer who participated in Potts' research: "breast cancer is not really about breasts, it's about life and death" (Potts, 2000:55). Thus, not only are women's surgical decision-making rationales unique, they do not provide an example of genetic exceptionalism.

When discussing the affect that mastectomy would have upon their bodies, women's accounts were constructed to accentuate their anxiety that breast loss would threaten their own, and others' perceptions of their normalcy. However, this threat did not offer an example of genetic exceptionalism. Women diagnosed with non-genetic breast cancer also face the same threat and express the same anxieties. I established that women wanted to look ordinary, and thus appear to be a 'normal' woman. Mastectomy

and nipple loss contested this. Given that both women diagnosed with breast cancer and women at-risk of HBOC face the same threat to their breasts and nipples, I concluded that the surgical decision-making accounts that women gave did not support the genetic exceptionalism thesis. The challenges to their womanhood that women at-risk of HBOC face are identical to those that breast cancer patients confront.

Women at-risk of HBOC will most likely have not developed symptoms of breast or ovarian cancer when they decide to seek medical intervention. By contrast, women undergoing mastectomy because of a malignant tumour will have experienced pathological symptoms. Thus being asked to decide whether to become a patient, undergo genetic testing and have a surgical procedure that is usually performed to combat disease, when you are healthy and asymptomatic is an unusual and relatively unique scenario. Whilst there are examples of asymptomatic patients undergoing surgery, such as a tonsillectomy, the patient will have experienced symptoms beforehand. Therefore, undergoing surgery because you are at-risk of a disease is an example of genetic exceptionalism, and demonstrates a difference between how genetic and non-genetic information is managed. Yet, as I discussed previously, the surgical management options available to women both with cancer and at-risk of cancer, are identical. This consistency in surgical techniques enables the exceptionalism thesis to be refuted once again.

Moreover, whilst the decision to undergo surgery when you have never been symptomatic is genetically exceptional and might provide evidence to support the notion of a revolution in health care, the rationales given to justify this decision were unexceptional. Much of the data I have discussed throughout this thesis has similarities with that reported in other studies. For example, like the at-risk women who participated in Hallowell's research (1999), the women in this study constructed and reacted to their heightened risk of HBOC as a moral issue. Likewise, Murphy (1998), in her study of infant feeding practise, found that women employed rhetorical strategies to manage their self-presentation, which was a form of self-protection. In relation to this study, because of the manner in which women constructed their accounts of their HBOC experience, the women's 'competence' could be seen through them appearing to act in a socially accepted moral and responsible manner. Consequently, they allowed themselves to be depicted as a good mother, wife, or daughter, and a competent patient

and woman. They also demonstrated that they acted altruistically. Women reported that they felt morally obligated to react to their genetic risk, and to take adequate risk-reducing measures because of their children. These rationales are comparable to those that Murphy (1998, 2000, 2003) discussed whilst examining women's decisions to breast or bottle-feed their newborn babies. Thus, the rationales that I received cannot be considered to be exceptional. I propose that women's decisions and the justifications they gave, are comparable in many ways with those given in relation to other health decisions.

In conclusion, I propose that whilst certain components of women's HBOC experience can be considered as genetically exceptional, these instances are too few to consider that being at-risk of HBOC creates an exceptional situation. The genetic exceptionalism thesis and my hypothesis, that **genetic medicine and the knowledge that it produces, is somehow special, unique or different from routine, non-genetic, everyday medical encounters and the knowledge resulting from such consultations** is rejected. Women's experiences of being at-risk of HBOC are not genetically exceptional.

Critical appraisal of thesis

The aim of the thesis was to question the genetic exceptionalism thesis in light of women's experiences of being at-risk of HBOC. Whilst this has been successfully achieved, it is important to acknowledge both the limitations and the accomplishments of the study.

In evaluating this thesis, it is important to acknowledge the exploratory nature of the study. Although the study was always intended to be a small-scale examination of women's experiences of being at-risk of HBOC, the difficulties in regards to accessing the clinical site and recruiting a sample, which I described in chapter four, limited the number of women participating in the research to just 16. If I had been able to recruit a greater number of women to participate, both in the interviews, and especially in the observations of the consultations, it is possible that the arguments made throughout the course of this thesis might have differed. It is also feasible to question whether the data I collected and the arguments made in light of it, are a product of the clinical setting at

Hospital X. The accounts that women gave or the consultations that I observed could have had a different content if I had recruited my sample from a different hospital, one not recognised a being a centre of excellence.

Similarly, it is also important to reflect upon whether the research became too engrained within the culture of the particular clinic and the clinical team's method of working. It is possible that my reliance on the clinical team at Hospital X created some form of bias in the outcome of the research. For example, Nurse H granted me access to both the clinical site and the sample subsequently recruited for the interview phase of the research. The clinical team assisted my acclimatisation or socialisation into the clinical setting by allowing me to perform many pilot observations and ask follow up questions when needed. Finally, it is important to acknowledge the role that the clinical team had in shaping the research design. In highlighting these influences, I am not suggesting that my autonomy as a researcher was lessened, nor consider that the factors discussed led to a negative outcome or research experience. Rather, I feel that it is important to acknowledge the possibility that outside influences may have indirectly shaped the research.

Reaching the end of the thesis and the doctoral experience necessarily means evaluating one's performance, and whilst it is all too easy to draw attention to the limitations of the study, it is far more difficult to highlight the successes. Whilst I did not address anything novel by way of topic, I believe that I was successful in making an original contribution to the field of medical sociology by examining women's HBOC experiences in light of the genetic exceptionalism thesis. To my knowledge, this dimension of the HBOC experience has not been considered thus far. Therefore, my arguments bring a new perspective to the medical sociological studies of women's health, breast cancer and perceptions of being at-risk of a genetic disease.

Recommendations for future lines of enquiry

I have argued that this thesis has made an original contribution to the field of medical sociology by adding a new perspective on the study of women's experiences of being at-risk of HBOC, by examining the topic in light of the genetic exceptionalism thesis. Consequently, it seems appropriate to suggest that this line of thinking offers the

potential for future lines of enquiry. As I have acknowledged, this was a small-scale exploratory study, which focused on the experiences of just 16 women, all of whom were treated at the same clinic. Further research might develop the foundations laid in this research, and extend the focus to a larger cohort of women, one drawn from different treatment centres. It would also be possible that, given an unlimited deadline, the original research design, as illustrated on page 92, could be followed. Such ethnographic research would lead to a longitudinal study of women's experiences of being at-risk of HBOC.

A second possibility for further research would be to investigate men's experiences of being at-risk of a BRCA related cancer. Although male carriers of BRCA genes have only a small risk of developing breast cancer, it is important that the male experience of being at-risk is not overlooked. Moreover, such research might examine social reactions towards male breast cancer, and thus touch upon a topic that is still very much taboo and not given the social awareness of its female counterpart.

A third line of enquiry could develop the arguments that I laid in chapter five, when questioning the identity of the patient. This topic has been relatively ignored by medical sociologists, whom thus far have only touched on the 'proband' issue (Finkler et al, 2003; Pilnick, 2002b). Greater investigation of the impact that genetics has upon the identity of the patient, will extend the work on the medicalisation and geneticisation of the healthy, and could prove fruitful and interesting.

Lastly, future lines of enquiry that lead on from the foundations laid by this research could focus upon the support given to the genetic exceptionalism thesis. In this thesis, I have concluded that the experience of women at-risk of HBOC cannot be considered to be genetically exceptional. Given the similarities that I have discussed between the experience of being at-risk of a genetic disease and being diagnosed with a sporadically developing illness, it would be interesting to give some thought to why the arguments for a genetic revolution and statements of support for the genetic exceptionalism thesis continue. It is proposed that many research teams may have a vested interest in promoting the genetic exceptionalism thesis. Put simply, genetic research has political weight, and in the current climate, is a popular area of study which has received a substantial amount of funding. Given the significant level of funding genetic research

has received, it is possible that the political, academic and scientific communities cannot afford to dismiss the genetic exceptionalism thesis.

Policy implications.

Whilst this research did not set out to offer policy suggestions, several of the findings have implications for future service provision. As I discussed in chapter one, the development of genetic services is a primary NHS goal, with £50 million funding promised in 2003 (Department of Health, 2003). Therefore, these recommendations seem timely.

i. The need for greater service provision.

> Much has been written…about the likely future impact of genetics on clinical care, the potential models for service provision, and the broader ethical, legal, and social issues….However, there seems to be little tangible progress in the capacity of the NHS to anticipate and respond to the accelerating momentum of technological change.
>
> Fears et al, 2000:933.

Fears et al's warning appears to have been unheeded by the NHS. Greater numbers of women are being referred to Family History Clinics, yet the resources of these clinics cannot match the demand that is made. At Hospital X, women at-risk were, understandably, left to wait until the doctors had seen symptomatic patients. However, this meant that any risk-reducing measures were delayed, thus placing the women at increased risk of developing cancer.

In the recent White Paper, "Our Inheritance, Our Future", the Government promised, "by 2006 genetic test results should be available to the following standards: ….within two weeks where the potential genetic mutation is already known (e.g. because another family member has already been tested) [and] within eight weeks for unknown mutations in a large gene" (Department of Health, 2003:30). However, given the pressure on current provision, it is unlikely that these aims will be met. Richards described the objective of improving the infrastructure of genetic care, as a "daunting task" (1999:314). Yet, this objective must be met.

It is proposed that in order to meet these objectives, the NHS would need to overhaul the current 'hub-and-spoke' design of genetic services. In the introduction to this thesis, I described the lengthy journey to Hospital X that one of the participants endured. If the current hub-and-spoke shaped infrastructure remains, such journeys will become more frequent with the expected increase in service use. Much needed policies must address the greater provision in staff numbers and clinical space that is required, in order that suitable provision and level of service can be provided to everyone at-risk of a genetic disease, regardless of where they live. Such a restructuring however, is unlikely to be well received by Whitehall in that it will require even greater levels of financial support when the NHS faces an on-going funding 'crisis'. Yet, as Richards notes, in order to address the needs of the patients, the restructuring of genetic services is a "nettle that the NHS must grasp" (1999:342).

ii. The need for greater education.

Whilst there is a great need for service development, there is also the need for clinical staff to have adequate training. The development of genetic services is likely to see genetic medicine expand into all areas of medical practice, as greater numbers of people seek to investigate their family history of disease. Consequently, "the clinical impact will be felt by all physicians and not just clinical geneticists" (Fears et al, 2000:934). However, there is concern that health professionals employed away from the regional genetics centres will be unprepared for this change (Donnai and Elles, 2001). Fears et al cautioned that "general practitioners will be among those most likely to confront the [genetic] issues, and in some ways are the least prepared professional group" (2000:934). It is therefore important that <u>all</u> health professionals are educated in genetic medicine, so that they can meet the needs of the patients.

It is not however solely the educational needs of health professionals that need to be addressed. Many of the findings discussed in this thesis raise questions about the women's understanding of the information that they received. In particular, it was noticeable that not all of the women took action to reduce the threat posed by their breasts <u>and</u> ovaries. Many only opted to reduce the threat posed by one body part. It was interesting to note that whilst some women were prepared to wait for breast cancer to develop, they dealt with their risk of ovarian cancer comparatively sooner after

discovering their heightened risk of developing the disease. This discrepancy in risk management might suggest that women may not fully comprehend the information that they are given, regarding the risk to both their breasts and ovaries. It is essential that women receive as much information as they require in order to make an informed decision, and obtain adequate and individualised psychosocial support that will allow them to come to terms with both the decision to have surgery and the outcomes of the procedure. However, there appears to be an information / understanding gap, or a problem with recall that must be addressed. It is proposed then, that audio-recordings of the consultation could be made and sent to women, who consequently would have a resource that could be returned to repeatedly. Such a recording may increase women's understanding of the nature of inherited risk and the aetiology of the HBOC, in addition to increasing their recall of the information provided by the clinical team.

Rationales such as those given by Jill and Judy demonstrated that breast and ovarian cancers, as well as the breasts and the ovaries, are perceived very differently. It seems as if women will react to the risk that they perceive is greatest, and will be influenced by their family's cancer history. Whilst families may have a stronger history of one particular cancer, a BRCA carrier is at-risk of both cancers, and greater prominence should be placed upon this risk. Rationales given to account for some of the decisions made, demonstrated that women might misunderstand the risks they face, react to whichever cancer they fear the most, or to the cancer that they consider to be the hardest to detect. Hopwood reported a similar finding, and described how "individuals with strong family histories may acknowledge an increase in risk, but frequently think in non-Mendelian terms and are more influenced by their particular familial experience of the condition. Their perceived vulnerability may be based on the burden of cancer in the family rather than on the hereditary nature of a faulty gene" (2000:388). The provision of an audio recording of the patient's consultation would help to address such a misunderstanding.

Similarly, the accounts given by the women illustrated that a problem may exist regarding women's ability to either recall or understand the information they are given regarding prophylactic surgery and reconstruction. I demonstrated how women failed to appreciate that whilst they were having 'immediate reconstruction', this did not mean that they would return from theatre with the same size and shape breasts as before their

operation. Moreover, the differences between reconstruction and cosmetic augmentation may need to have greater emphasis placed upon them. Many of the women reported that they were shocked that the aesthetic outcome of their reconstruction may be less than perfect, and would not match the visual results of cosmetic breast augmentation. Furthermore, given the significance that it had for the women I interviewed, one must ask why the topic of nipple loss has been relatively ignored by other studies, when it appeared to have so much influence upon women's surgical decision-making and subsequent psychological and emotional recovery.

The psychological and emotional experiences of women at-risk of HBOC are comparable to those of women who undergo surgery for breast cancer. Women at-risk also reported feelings of loss and grief following their prophylactic mastectomy, and as such should be treated the same as breast cancer patients. Consequently, provision should be made for any emotional and psychological support that these women need. Many of the women participating in this research recounted 'horror' stories of their in-patient stay, and described how they felt ward staff perceived their experience to be emotionally different from women diagnosed with breast or ovarian cancer. However, as I discussed in chapter eight, the social, emotional and psychological impact of prophylactic surgery was similar to the published accounts of breast cancer patients. It is therefore important that health professionals respond to the needs of the women they treat, and recognise the emotional trauma of a prophylactic mastectomy is no less than that of a mastectomy performed to remove a tumour.

Lastly, in terms of the possible implications for cancer care policy, women's accounts illustrated that there was a lack of comprehension regarding the risk to male carriers of BRCA genes. For example, Joanna reported that she had not been told about the risks her sons faced from both breast and prostate cancer, and other women only seemed concerned about the risks posed to their daughters. Thus, the risks that men face, should they inherit a BRCA gene, need greater prominence given to them during the consultations.

A revolution in health care?

In relation to the findings of my research, it seems that the arguments for genetic exceptionalism and a revolution in health care have been overstated. The experiences and rationales reported by the women were consistent with justifications given for decision-making involving non-genetic issues. It is for this reason that I have concluded that the experiences of women at-risk of HBOC are not genetically exceptional, and as such, do not provide an example of a widespread revolution in health care.

For women at-risk of HBOC, genetic information confirms what they have lived with and known for many years: they have a family history of breast and/or ovarian cancer, and are at-risk of developing either disease. Whilst news of their carrier status does enable women to take steps towards prevention, prophylactic surgery is not 100% effective. Knowing one's risk does not enable cancer to be prevented in all cases. Although genetic knowledge is powerful and enables at-risk individuals to undertake risk-reducing measures, it does not provide absolute certainty. Genetic information provides probabilities, not horoscopes (Anon, 2004).

The Shadow Health Secretary Liam Fox (2003) commented, "we mustn't over hype what genetics can do", and Rose concluded that, "overemphasising the role of genes ignores the clear and present sources of most of the problems of life" (2004:3). As I have demonstrated throughout the thesis, for the most part, the experience of women at-risk of HBOC does not differ substantially from the illness or disease experience of any other patient facing breast or ovarian cancer. Therefore, I cannot support the notion that having a genetic illness, or being genetically at-risk of a disease, is "qualitatively different" from its non-genetic counterpart (Friedman Ross, 2001:145). The genetic exceptionalism thesis is therefore dismissed. Furthermore, in light of the similarities between the experience of being at-risk of HBOC and being diagnosed with breast or ovarian cancer, I am also unable to support the idea that the medical management of women at-risk of HBOC has constituted a revolution in health care.

Given the similarities I have described, it seems that the genetics revolution has not been as successful as we have been led to believe. Sample considered:

> Few revolutions happen without misplaced hopes – and the fledging genetics revolution of the 1990s was no exception. If you believed the hype, as soon as scientists mastered how to handle genes, humanity would be able to take on nature at its own game.
>
> Sample, 2004.

Whilst scientific and medical knowledge has developed because of the completion of the HGP, away from the scientist's laboratory, the application of genetic technology has not progressed as quickly as had been hoped. Moreover, that what can be done, is unable to offer any promises of certainty. For example, although it is possible to investigate a woman's risk of carrying a positive BRCA mutation, all the receipt of a positive BRCA test result can do is to offer a probability that cancer will develop. A genetic test result cannot say for certain if, when or even how HBOC might manifest. Therefore, is the information provided by the genetic test any more informative than relying on non-genetic material, such as patterns of disease within a family? Secondly, even with this 'new' type of information, the risk management options available to women at-risk remain the same as those offered to women diagnosed with breast or ovarian cancer: mastectomy, oophorectomy, hysterectomy and chemotherapy. These treatments are not only genetically unexceptional, but having been practised for decades, neither do they represent a revolution in health care.

Given the similarities that I have discussed between the experience of being at-risk of HBOC and being diagnosed with sporadically developing breast or ovarian cancer, John Reid's (2003) statement with which I began this thesis, that "we are standing on the threshold of a revolution in health care", appears to be have been a somewhat over exaggeration of the influence that the HGP would have upon the management of specific diseases.

> The genetics revolution has not lived up to the hype.
>
> Caulfield, 2000:445.

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SECTION III: Appendices.

1. Glossary of medical and surgical terms.
2. Overview of the sample.
3. The patient information sheet.
4. The consent form.
5. CA notation.

Appendix One: Glossary of Medical Terms.

Ablation: Removal of a body part, or destruction of its function, via surgical or chemical means.

Adjunct: Also referred to as 'adjuvant'; an additional form of treatment.

Allele: Two or more genes that occupy the same position on a chromosome.

Anterolateral: The front side of the chest wall.

Areola: Small pigmented area surrounding the nipple.

Autosome: Chromosome (structure containing genetic material - DNA), that is not a sex chromosome.

Autosomal Dominant Disorder: Caused by a genetic fault in a single copy of the affected gene that overrides the normal functioning copy.

Autosomal Recessive Disorders: Two copies of the affected gene need to be inherited for the individual to be at-risk. Inheritance does not always lead to the manifestation of disease.

Axillary Dissection: Procedure that surgically cuts apart the axilla (armpit), to identify, examine and remove tissue for diagnosis and treatment.

Cauterisation: Procedure that scars, burns or cuts away tissue, using heat, electric current or caustic chemicals. In contemporary medical practice, the term 'diathermy' is used to describe cautery.

Clavicle / Clavicular: The collarbone.

Cowden's Disease: Causes multiple haematomas, malformations that resemble tumours; linked to mutation in PTEN gene.

DCIS: Ductal Carcinoma In Situ, sometimes referred to as 'pre-cancerous'.

DNA: Deoxybribonucleic acid; stores genetic information, encoded into two chains (double helix) and patterns of adenine (A), cytosine (C), guanine (G) and thymine (T).

Excision: Operative removal of organ or tissue.

Genotype: The specific genetic composition of an individual.

Huntingdon's Disease*:* A progressive neurological disorder. Suffers experience involuntary movements and periods of rigidity, amongst other symptoms. The disease is usually fatal, with death occurring 15-20 years after onset of neurological or psychological impairment (Huff, 2004).

Inframmary Incision: Surgical incision below the breast.

Ipsilateral: The same site. For example, a woman may be diagnosed with a recurrence of breast cancer in the ipsilateral breast.

Karotype: An individual's chromosome characteristics.

Li-Fraumeni Syndrome: Cancer family syndrome; tendency to develop a range of tumours, including breast, brain, bone and adrenocortical carcinomas and leukaemia.

Ligature: Procedure which bands together, or ties a structure, so as to constrict it.

Lymph Nodes: The lymphatic system produces and stores cells that fight infection and disease. Lymph nodes are small organs located in the lymphatic system, which trap cancer cells.

Lymphodema: Swelling, resulting from obstruction or accumulation of lymph nodes.

Mastectomy: Excision of the breast.

Metabolites: Product of metabolism – chemical changes in the tissue; also involving catabolism – breaking down of complex chemicals into simple ones.

Mitoses: Process of cell reproduction.

Oophorectomy: Also known as ovariectomy; removal of one or both ovaries.

Pectoral Muscle: Muscles of the anterior (front) chest (pectoral) wall.

Penetrance: Likelihood that an individual who carries a mutation will develop the disease associated with the mutated gene.

Peritoneal: Lining of the abdominal cavity.

Phenotypes: Appearance of an organism, resulting from genetic and environmental causes.

Pleomorphism: Occurring in more than one form.

Predictive: To identify an individual at increased risk of potentially developing a hereditary disease at some point in the future.

Pre-symptomatic: To identify a genetic disorder prior to onset of any associated symptoms.

Radical Mastectomy: Also known as the 'Halstead', simple' and 'total' mastectomy. Involves the excision of the entire breast, including nipple, areola, overlying skin, pectoral muscle, lymphatic bearing tissue in axilla (armpit) and other neighbouring tissue.

RNA: Ribonucleic acid; found in all cells.

Serum CA 125: Blood test that monitors presence of cancer cells.

Sickle cell anaemia: An inherited, congenital form of anaemia, in which there is an absence of red blood cells, and those that exist are abnormally shaped.

Subcutaneous: Beneath the skin.

Tay Sachs*:* A fatal genetic disorder in children that causes progressive destruction of the central nervous system, leading to a premature death, usually by the age of five years old.

TRAM flap breast reconstruction: The transverse rectus abdominis musculocutaneous flap reconstruction, uses a flap of the patient's lower abdominal tissue to build a breast.

Appendix Two: Sample Overview.

The following profiles briefly describe each of the women's characteristics and journey to the family history clinic. All names mentioned throughout this thesis, those of the women interviewed and observed, the hospital staff and the names of the hospitals, are pseudonyms.

Caitlin.

Caitlin's husband found a malignant lump in her breast when she was 26 years old. She underwent a total mastectomy in the cancerous breast and a prophylactic mastectomy in the contralateral breast. Both breasts were reconstructed at the time by a senior surgeon who has since retired. Her breast implants were replaced at the beginning of 2003, as problems had started to develop with the existing implants calcifying and hardening. Caitlin tested BRCA 1 positive, and had chosen to undergo screening for ovarian cancer whilst she completes her family. Upon completion of her family, she intended to undergo a prophylactic oophorectomy or hysterectomy. At the time of the interview, Caitlin was married and had a two year-old son. She was 28 years old. She had a twin sister, Amy, who was also BRCA 1 positive, but was unavailable to participate in the study.

Cassie.

Cassie was referred to the hospital aged 43 years old, following a family history of breast cancer on her maternal line of inheritance, which resulted in multiple deaths in her family. She underwent genetic testing, and received a positive BRCA1 result. A year later, Cassie decided to undergo prophylactic surgery, and had a bilateral mastectomy and oophorectomy. When interviewed, Cassie was 46 years old, married with a 24-year-old daughter.

Jade and Julie.

Sisters Jade and Julie, aged 28 years old and 32 years old respectively, attended a consultation with Mr Martin, and subsequently participated in the interview phase of the study. They had a family history of ovarian cancer along their maternal line of inheritance, and had decided to undergo genetic testing when Julie wanted to become

aware of her carrier status as she wanted to start a family. Jade tested BRCA 1 positive, whilst Julie tested negative. Jade was referred to the clinic to discuss the risk that a BRCA 1 mutation posed to her breasts. Julie attended both the consultation and interview to support her sister. Jade was single, whilst Julie lived with her partner and young son.

Jen.

Jen was 25 when she tested BRCA1 positive. She was referred to the Family History Clinic because her Mother carries a BRCA1 mutation. At the time of the interview, Jen was 28 years old, and had chosen to have annual screening rather than undergo any prophylactic surgery. She was divorced and had two children, a six year-old son and a four year-old daughter.

Jill.

When interviewed, Jill was 38 years old, and deciding whether to undergo prophylactic bilateral mastectomy. She has a strong family history of ovarian cancer in the maternal side of her family. She tested BRCA2 positive at 35 years old and underwent a prophylactic hysterectomy, which was carried out by consultant gynaecologist. Jill was married with three children.

Joanna.

At the time of the interview Joanna was 52 years old, and had decided not find out if she carried a genetic mutation that would signify a predisposition towards HBOC. She had a history of breast cancer along the paternal line of her family. Her Aunt tested BRCA2 positive. Joanna was married, with three adult children.

Judy.

Judy had a family history of ovarian cancer in the maternal side of her family. She had been involved in a screening programme since 1994, and tested BRCA2 positive aged 39 years. She underwent a hysterectomy a month after receiving the genetic test result. Judy was 42 years old when interviewed and married with a 16 year-old daughter.

Laura.

Laura was diagnosed with DCIS in her mid 30s. Laura also had a family history of breast cancer in her maternal line and consequently was advised to have bilateral prophylactic mastectomies. However, when the procedure was carried out, cancerous cells were found. Consequently, Laura had undergone regimes of chemotherapy and radiotherapy. Because of her family history and early onset breast cancer, Laura chose to have genetic testing, and discovered that she carried a mutated BRCA1 gene. When interviewed, Laura was in her late 30s, married and had three daughters. She was the younger sister of Trisha (see below).

Louise.

Louise had a history of breast cancer along the paternal line of her family. She learnt that she was at-risk of hereditary breast and ovarian cancer from her cousin, who had tested BRCA1 positive. At the time of the interview, Louise had just received the news that she had tested negative for the genetic mutation. She had a five year-old daughter. Louise was also involved in the observation phase of this study.

Trisha.

When interviewed, Trisha was 40 years old, and waiting to be admitted into hospital to undergo prophylactic bilateral mastectomies, reconstruction and prophylactic oophorectomy following receipt of a positive BRCA1 test result. Trisha's mother died of breast cancer when she was 18 years old, and although she discovered a benign lump in her breast when she was 27 years old, it was not until her younger sister, Laura (see above), developed breast cancer and tested BRCA1 positive, that Trisha recognised that she was at high risk of HBOC. Trisha was married and had two teenage children, a son and a daughter.

Zoë.

Zoë was 28 years old when she was referred to the Family History Clinic because of a strong history of breast cancer in the maternal line of her family. In addition to herself, Zoë's mother and brother tested BRCA2 positive. After receiving the test result, Zoë underwent prophylactic bilateral mastectomy, followed by reconstruction initially using tissue expanders and valve implants which were subsequently filled with saline. When

interviewed, Zoë was 32 years old, living with her partner and five months pregnant with her third child, a son. Her daughter was 11 years old and her son 13 years old.

In addition to the interviews, five observations were carried out. Louise, Jade and Julie participated in both the observation and interview phase of the study. The following profiles describe the women who participated solely in the observations of consultations.

May and Linda.

May was in her late 50s when she was referred to the Family History Clinic by her GP. Also attending the consultation was her eldest daughter, Linda, who was 35 years old, and married with four children, including one teenage daughter. Both of May's sisters developed breast cancer in their 50s and early 60s, and her youngest daughter, Kate, was diagnosed with breast cancer in her early 30s. A clinical geneticist and nurse genetic counsellor carried out the consultation.

Susan.

Susan was 32 years old when her consultation was observed. She had a family history of breast cancer along her maternal line of inheritance. A senior consultant and breast surgeon carried out her consultation. It is unknown whether she decided to have genetic testing, due to the constraints placed upon the research to enable access and ethical approval to be granted. Susan attended the consultation with her husband. They had two young daughters.

Wendy.

Wendy was diagnosed with breast cancer aged 44 years old and had a recurrence in the ipsilateral breast 12 months later. Treated at Tall Trees, a private hospital, Wendy underwent a mastectomy, followed by radiotherapy and chemotherapy. The consultation observed occurred when she attended the Family History Clinic, aged 46 years old, to discuss the possibility of genetic testing. Wendy had two young daughters. Her marital status was unknown.

Doctors.

The women spoke about six doctors during the interviews. Four doctors were observed during the course of the observation phase of the study.

Professor Brown.

Professor Brown was a retired NHS Consultant Surgeon. Prior to his retirement, he was the head of department at Hospital X in which the research was sited. At the time of the research, he was employed at Tall Trees, a private hospital.

Miss Walker.

Miss Walker was a NHS Gynaecologist & Surgeon at Hospital X.

Mr Parker.

Mr Parker was a NHS Breast Surgeon, employed at one of the regional satellite hospitals.

Professor Russell.

Professor Russell was the current head of department at Hospital X. He was also a NHS consultant breast surgeon.

Mr Martin.

Mr Martin was a NHS consultant breast surgeon at Hospital X. He specialised in reconstructive surgery & family history of breast cancer.

Dr Cross.

Dr Cross was a NHS Breast Surgeon, previously employed at the Family History Clinic.

Dr Wright.

Dr Wright was a NHS clinical geneticist at Hospital X.

Additionally, two nurses participated in the study.

Sophie Wright.

Sophie Wright was a senior breast care nurse at Hospital X, and acted as my gatekeeper.

Mary Taylor.

Mary Taylor was a specialist nurse genetic counsellor at Hospital X.

Appendix Three. Patient Information Sheet[48].

Dear _____

You have a family history of breast or ovarian cancer for which you have attended the Family History Clinic at X Hospital. Please read this information sheet carefully and feel free to ask any questions you may have about what it contains.

Emma Rowley who is a PhD student in the Institute for the Study of Genetics, Biorisks and Society (IGBiS) at the University of Nottingham is conducting a research project to study the decision making experience of women at-risk of breast and ovarian cancer. This project has the full co-operation of the Family History Clinic at Hospital X.

In this study, Emma is trying to find out how women make their decision about whether or not to undergo genetic testing and subsequent decisions that may be made regarding surgery or screening if a genetic mutation was found. This information will be useful for the Family History Clinic and may them to offer a better service in the future enabling them to meet the needs of the people using the service more successfully.

You are under no obligation to take part and if you decide not to participate it will not affect at any time the care you receive.

With your permission, your conversation with Emma will be audio recorded which will be used for her PhD thesis. The tape and the information from this will only be used for research purposes and when the research is written up there will be nothing to identify which patients have taken part, or who said what. The audiotapes will be destroyed in accordance with University policy when no longer required for the purposes of the study. If you are unhappy about being recorded, please let Emma know.

Emma is not medically trained and not employed either by the Family History Clinic, Department Y or Hospital X. She cannot give you any medical information about breast or ovarian cancer and there is no risk to you from taking part in this research.

Thank you for taking the time to read this information.

[48] This letter was originally on hospital letter-headed paper.

Appendix Four. Interview Consent Form[49].

Title of the project: Decision-Making Amongst Women At-Risk Of Hereditary Breast And Ovarian Cancer.

Investigators: Lead Investigator: Emma Rowley (IGBiS).
Supervisors: Professor Robert Dingwall, Dr Sam Hillyard (IGBiS) Dr Alison Pilnick (Sociology).
Clinical Team: Doctor E, Doctor F and Nurse H.

Participants should complete the whole of this section themselves.

- Do you understand that you are free to withdraw from the study
  - at any time YES NO
  - without having to give a reason YES NO
  - without affecting your medical care YES NO

- Do you agree to interviews being recorded? YES NO

- Do you agree to take part in this project? YES NO

Participant's Signature _____ Date _____

Participant's Name (in BLOCK CAPITALS)

I have explained the study to the participant and she has indicated her willingness to participate.

Researcher's Signature _____ Date _____

Researcher's Name (in BLOCK CAPITALS) EMMA ROWLEY

[49] This form was originally on IGBiS letter-headed paper.

Appendix Five: CA Notation[50].

(0.5)	Gap in speech in tenths of seconds.
(.)	Gap in speech less than (0.2).
=	Latching utterances.
[	Onset of concurrent speech.
::	Elongation of sound; more colons used indicates greater elongation of sound.
word	Word stressed.
hh	Breath sounds.
((words in brackets))	Description of actions.

However, within the text, words that are **bolded** should not be read as having a CA significance. Whilst CA notation does use bolded text, in this thesis, bolded text is used to emphasise sections of the data.

[50] CA symbols: *see* Sacks, H. Schegloff, E. and Jefferson, G. (1974) A Simplest Systematics For The Organisation of Turn-taking For Conversation Language **50**: pp 696-735.