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Living With a New Normal: Women's Experiences Following Treatment for Early-Stage Breast Cancer or DCIS

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Abstract

This thesis explores the experiences of 24 women who were treated for early-stage breast cancer (ESBC) or ductal carcinoma *in situ* (DCIS) in the UK between 6 months - 29 years previously. These experiences are important because better detection and treatments have resulted in increasing numbers of women surviving for longer. My own experience of ESBC, revealed in extracts from my research journal, brought both benefits and drawbacks to the research but ultimately resulted in a unique perspective. Participants accessed through a press release were interviewed in-depth. Data were then analysed using narrative and thematic analysis. Bury's (1982) concept of illness as a biographical disruption was used as the theoretical framework but a consideration of the context revealed that ESBC/DCIS is not always experienced as disruptive. Analysis also revealed that the post-treatment period can present further challenges as loss of medical support can coincide with withdrawal of social support. Some participants reported feeling isolated and vulnerable post-treatment. Often their feelings were at odds with public expectations based on media representations of 'successful' breast cancer survivors, and the high profile of breast cancer charities which can suggest 'pink fluffy' imagery. Ongoing disruption to their bodies and relationships can mean that women feel in an ambiguous state which can be likened to a state of liminality (Turner, 1969). The current research combines the concepts of biographical disruption and liminality for the first time in a study of ESBC/DCIS, therefore enabling consideration of gendered aspects of the experience. In particular, the importance of breasts to femininity and sexuality can have implications for identity and relationships. I argue that, whilst women do not return to the 'normality' of pre-diagnosis, the wide range of experiences and emotions in the post-treatment period can be conceptualised as a 'new normal'.

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Preface

June 8th 2012

It is quite fitting that I sat down to write this preface five years to the day that I was told that they had found a cancer in my left breast and pre-cancer cells (DCIS) in my right breast. At the time, it was a total shock. It shook the foundations of my being. Trying to comprehend what I was being told, I panicked at the thought of leaving my sons who were just 11 and 9. It couldn't be right. I was fit and well. There was no history of breast cancer in my family – my Mum was still alive aged 78 with no major health problems. It couldn't be possible. Obviously I knew I had a lump, that's why I had gone to the doctor and then for tests at the hospital, but I was sure it would be a cyst or something – I had problems with mastitis when I was breastfeeding. And that was another thing – breast cancer was supposed to be where women had no children, or had not breast fed. I had done both. And I was too young, I was only 44.

What happened to me when I had cancer transformed my life. All that had seemed solid and permanent in my world suddenly became unstable and shaky. I clung on to what mattered to me most and let the rest fall away. The work I was disillusioned with, the people I knew who drained me to be with – all got left behind. And one of the things that I clung to in the wreckage and what kept me afloat was studying. Being off work was good for allowing me time to recover from my treatments but studying was my mainstay during the long periods in between. I took the second module of an MA I was

working towards with the Open University. I was avoiding people to make sure I stayed free of infections that would delay my treatment so I was alone much of the time. But studying took me to a different place, a cancer-free place. I kept an on-off journal at the time and I wrote about going to the postgraduate open day at the University of Nottingham that the best thing was not talking about cancer at all during that day. Which seems ironic now that I am here and I talk about, read about, and write about cancer every single day. But now it is on my terms.

When I returned to work I took an offer of voluntary redundancy and came to the University of Nottingham where I had been granted the fees for an MA in research methods. After that I was fortunate to be successful in getting a studentship which enabled me to pursue the current PhD study.

As part of the MA I conducted a pilot study in which I interviewed six women who had been treated for breast cancer. Two participants, who were also my friends, had secondary breast cancer and have since died. The effect that their deaths had on myself and the research project is discussed in the methodology chapter.

Cancer arrived in my life as an intruder and I wanted to get rid of it as soon as possible. But its shadow remains with me. It will never go away so I try to get along with it. I find out more about it. I talk to people who live with cancer as well.

Cancer was not and is not something I would ever say was a good thing to happen to me. But I am determined to get something good out of it. I want to use my enthusiasm for

studying, and the knowledge I have gained through my own experience, to further the knowledge in this area.

I realise that not everyone has the same blessings that I do and that my experience can never be the same as anyone else's but we have walked the same corridors, sat in the same waiting rooms, smelled the same smells and heard the same sounds. Perhaps that allows me a different level of understanding.

There are of course problems with studying something so close to my personal experience. Just as looking at a close-up can restrict your view of the bigger picture, there may be times that I will need to step back to regain a sense of perspective. Some of the stories that the women tell me are emotional and painful to tell and to hear but I need to put that emotion to one side as I consider what is being said underneath the actual words that are used.

This is my challenge but I owe it to the women who have shared their stories with me, to do it as well as I can.

Chapter1. Introduction and research context

This is an interview study which aims to explore the experiences of 24 women who have been treated for either early-stage breast cancer (ESBC) or ductal carcinoma in situ (DCIS).

At the present time, breast cancer is by far the most common type of cancer affecting women in the UK, with 1 in 8 affected during their lifetime. In 2009 almost 48,500 women were diagnosed with breast cancer and 11,556 women died of it in 2010 (Cancer Research UK, 2012). Breast cancer is diagnosed by clinicians as either primary (or early stage) which means that it has not spread beyond the breast or the lymph nodes, or secondary where it has spread to another area of the body. It is not known whether the cancer has spread until some of the lymph nodes have been removed and examined. DCIS stands for ductal carcinoma in situ which describes non-invasive calcium deposits in the milk ducts which may or may not become cancerous. At the present time there is no way of knowing whether the cells will become cancerous.

Consequently DCIS is treated in the same way as cancer which is through surgery to remove the pre-cancer cells as a lumpectomy or the entire breast (mastectomy). In 2009, 5,600 women in the UK were diagnosed with DCIS. Both ESBC and DCIS are different to secondary breast cancer which has spread to other parts of the body such as to the lungs or bones, and which is usually deemed incurable (Cancer Research UK, 2012).

Typically there are no obvious indications of primary breast cancer other than a lump in the breast tissue which may be found either by the woman herself through self-examination, or as a result of a mammogram (x-ray of the breast). Breast cancer is different to many illnesses in that, although there are many theories about its aetiology, the exact cause remains unknown. Also, following treatment for primary breast cancer there is the possibility of recurrence and subsequent development of secondary breast cancer (www.breastcancer.org accessed 10/1/12). This may create a perception of never being fully cured which can result in an ongoing sense of anxiety, as will be discussed in chapter 5 of this thesis.

The young age of women being diagnosed is also a matter of note with Scambler (2008) commenting on significant differences between the sexes in the age at which cancer (of all types) occurs. Incidence rates for females aged 30-45 are far higher than for men of the same age, with 70% more females than males being diagnosed between the ages of 30 and 34. This difference can mainly be attributed to the prevalence of breast cancer which, although it also occurs in men, usually affects women. In 2009 48,417 women were diagnosed in the UK compared to 371 men (<http://www.cancerresearchuk.org/cancer-info/cancerstats/keyfacts/breast-cancer/> accessed 23/8/12). Even though 80% of cases of breast cancer occur in women aged 50 or over, it nevertheless remains a significant threat for younger women of childbearing age. It can have implications in respect of femininity, sexuality and fertility, as well as mortality.

Encouragingly, life expectancy has increased with higher numbers of women diagnosed with breast cancer surviving more than twenty years after treatment. According to the leading UK cancer charity, Macmillan, breast cancer median survival time has doubled since the 1970s and has been more than 10 years since at least the early 1990s (<http://www.macmillan.org.uk/Documents/AboutUs/Newsroom/Factsheets2011> accessed 24/1/12). What this means is that there are more women who are living with breast cancer and the possibility of recurrence. Consequently, new ways need to be found to help women to adjust to life post-treatment.

Discussing his recent bestselling book, *The Emperor of all Maladies* (2011a)¹, Siddhartha Mukherjee, an oncologist and assistant professor of medicine at Columbia, argues that for a woman who has experienced breast cancer:

Cancer will become a chronic condition for her; she will live in its immediate shadow for decades, never quite certain about her outcome...(H)aving entered the world of cancer, her life will be permanently altered..for her, cancer will become the new "normal" (Mukherjee, 2011b:27)

But what does this new normal look like? This thesis draws on data from the narratives of 24 women who have completed treatment for either ESBC or DCIS between 6 months and 29 years previously, to find out what constitutes their 'new normal'. The analysis presented here will explore first of all

¹ As an indication of the amount of public interest in the subject of cancer, Mukherjee's book *The Emperor of All Maladies: A Biography of Cancer*, was listed in the top 10 books of 2010 by the *New York Times* and won the Pulitzer Prize for General Non-fiction in 2011

how bodily changes have impacted on their perception of themselves in terms of femininity and sexuality and secondly, how their experiences have been shaped by interpersonal relationships both during and after treatment. This will help to further our understanding of what it is like to live in the afterlife of ESBC/DCIS and its treatment.

The importance of studying this period is reinforced by cancer support networks in the UK such as Macmillan and Breast Cancer Care, with the latter being the biggest charity providing support for women affected by breast cancer. It is being recognised that people do not just need support when they are going through cancer treatment but they also have ongoing issues throughout the rest of their lives. In response, Macmillan are trialling a scheme providing volunteers to help people who have survived treatment yet still need practical and emotional support (Williams, 2012) and Breast Cancer Care supply a resource pack to help women deal with issues that arise, such as fear of recurrence, loss of medical and social support and bodily changes (<http://www2.breastcancercare.org.uk/publications/moving-forward/moving-forward-support-people-living-beyond-breast-cancer-sm23>).

I will now set out the broader context in which the current research took place. It is important to outline at the outset, some of the major influences that may have affected the participants' experiences and also the reactions of other people to them. This will incorporate media representations of women with breast cancer including those in popular dramas such as *Coronation Street*; the widespread use of metaphors in talking about cancer; and awareness raising campaigns which use what might be termed 'pink positivity' to try to

engender a feeling of unification amongst women. Kaiser (2008) who explored the meaning of survivorship with 39 women, reports the conflict between cultural images of breast cancer survivors and women's own feelings of fear and uncertainty. This tension will be explored in chapter 7.

Media

Over the past 25 years breast cancer has emerged from being a taboo topic into one that is openly discussed in the public realm. Saywell et al (2000) observe that breast cancer is no longer confined to the health pages of women's magazines but regularly makes news headlines. Similarly, Corbett & Mori (1999) report that in 1960 there were just 3 stories about breast cancer in the New York Times and all US Magazines and by 1995 there were 149 stories in the same sources.

A quick *Google* search for the term 'breast cancer' in UK headlines for one four-week period in 2012 yielded 146 results. Headlines tend to focus on either risk factors (for example 'Breast cancer risk in too little sleep' *Daily Express* 30/8/12); new treatments (for example 'New drug is holy grail to fight breast cancer battle' *Daily Express*, 13/9/12) or preventative measures (for example 'Six hours of housework per day may reduce risk of breast cancer: study' *Daily Telegraph* 4/9/12). This last example highlights the way that research findings can be manipulated by the press. It seems that the research upon which the headline was based concluded that women who are physically active are 13% less likely to develop breast cancer. However the newspaper chose to interpret this in a patriarchal manner and thus reinforce gender stereotypes as well as insinuating that some women may be to blame for

causing their own cancer by not working hard enough in the home.

One of the reasons for the reduction in the taboo surrounding breast cancer is that many well-known women, pioneered by Betty Ford, have spoken publicly about their experience with the disease. Perhaps the biggest impact on public consciousness was Kylie Minogue's diagnosis of breast cancer in 2005 when she was just 36 years old. It was shocking that it should happen to someone not only so young but also someone who seemed to have all the trappings of success, good looks and talent. It was an indication that breast cancer really could happen to anybody and that youth, wealth and beauty did not offer immunity.

It is indicative of the current fascination with celebrity culture that people look to celebrities for examples of how they should view their own life. The high-profile given to survivors of breast cancer such as Kylie Minogue, Jenni Murray, Cynthia Nixon, Nancy Reagan, Sheryl Crow and Olivia Newton John may have fostered an expectation of a positive outcome from a breast cancer experience. These publicly played out illnesses not only highlight that breast cancer can be survived, but that people could even benefit from the experience. For example Olivia Newton-John said 'I realise I am blessed to be alive..I don't think I would have grown..without that experience' (www.breastcancersuccess.com/olivia.htm accessed 8/2/10). When the cover of *Woman* magazine featured *Coronation Street* actress Sally Dynevor the accompanying headline read: 'Sally's battle: I looked at my kids and thought, they need me'. Seale (2002) argues that the media ascribe 'magical powers' to celebrities who have cancer. They describe people's will to

'beat' cancer and suggest that they were able to survive by power of thought and will.

People see a celebrity recovering from breast cancer which can encourage positivity but Moore (2008) argues that an emphasis on positive thinking and self awareness can make the distressing aspects of the cancer experience invisible. In her study of cancer patient's talk, Wilkinson (2000:366) argues that women with breast cancer often display a 'moral imperative' to think positively. In interviews she noticed that her participants often couched negative comments in a positive statement. For example one woman said: 'I am a positive person, but I could cry at the drop of a hat, a lot of the time'. Similar linguistic devices were employed by some of my participants, as will be discussed in chapter 7.

Metaphors

Despite the prominence of the topic in the media, Bowker (1996) believes that even today people are uncomfortable discussing cancer which has a historical perception of being an incurable disease. Peters-Golden (1982) argues that this discomfort often manifests itself in the avoidance of ill people and referring to cancer using innuendos and euphemisms such as the 'Big C'. Broom (2001) highlights how the language used to describe cancer is awash with metaphors and that cancer is itself used as a metaphor for moral and evil problems in society. For example, these are two newspaper headlines: 'Senior police officer blames family breakdown for violent crime 'cancer' destroying society' (*Daily Mail* 7/9/07); 'Senior Tory slams 'cancer' of corruption in UK police' (*The Observer*, 23/12/12). Sontag (1991) argues that it is not helpful to

people who are living with cancer to see it being associated with societal evils. She suggests that metaphors can impact on how people experience cancer and how others behave around them. For example, Moore (2008) argues that the metaphors used in breast cancer literature enhance the sense of vulnerability by describing the disease as a threat or attack which may be misleading given that cancer cells originate and reproduce within the body. According to Sontag (1991), the inference is that if a person does not 'fight hard enough', healthy cells would be overwhelmed by cancerous invaders, leading to a loss of self. Military language is employed in the medical narrative as well as by patients and the general public. For example people are said to be 'fighting' or 'battling' the disease and Reisfield & Wilson (2004) highlight an advertisement for a drug used to treat early breast cancer which features a woman wearing pink boxing gloves. However, the use of military metaphors may not be a useful way of speaking about cancer for those people actually living with it. With limits to the 'weapons' that patients can employ against an invisible, unpredictable 'enemy', Reisfield & Wilson (2004) argue that the martial comparison implies a failure of the patient rather than failure of treatment. Additionally, if someone opts out of treatment they have to deal with guilt at 'letting the side down' by showing cowardice rather than being seen as someone who has made an informed decision not to have treatment that may have a detrimental effect on the quality of the rest of their life. Journalist John Diamond (1998) reflected on his own cancer experience in his book, *'Because cowards get cancer too'* and sums it up well:

'My antipathy to the language of battles and fights has nothing to do with pacifism and everything to do with a

hatred for the sort of morality which says that only those who fight hard against their cancer survive it or deserve to survive it – the corollary being that those who lose the fight deserved to do so’ (Diamond, 1998:10)

Women’s narratives collected as part of this project revealed that they drew upon numerous metaphors when describing their experiences. As Sontag (1991) argues, metaphors are abundant in descriptions of illness; therefore the use of metaphors will be a common theme throughout the analysis.

Charity campaigns

The extra attention afforded to breast cancer also extends to charities. The creation of charities that promote awareness of breast cancer has been a ‘bottom up’ response of breast cancer patients frustrated at the lack of information on the subject of their illness. For example, Betty Westgate founded Breast Cancer Care after recognising a need for non-medical help (*Society Guardian*, 2001). She found that whilst doctors are able to describe the physical aspects of the disease, the social aspects such as the effect on family and wider society are not addressed by the medical perspective, an argument reinforced by Helman (2007).

Today there are more charities concerned with breast cancer than with any other type of cancer. For example there is just one lung cancer charity compared to at least nine breast cancer charities despite the fact that, according to Cancer Research UK (2012), more women die of lung cancer each year (21% compared to 15% of female deaths as a result of breast cancer). This may be because, as Chapple et al (2004)

argue, lung cancer attracts a greater degree of stigma, and hence less public support, because of its strong association with smoking.

Recent years have seen an explosion of the pink merchandise associated with breast cancer awareness campaigns and charities. The pink ribbon campaign was initiated in the USA by Evelyn Lauder in 1992. The aim was not just to raise money but was prompted by anger at the lack of publicity for women's health issues generally and breast cancer in particular (Moore, 2008). The ribbons were sold at cosmetics counters and quickly gained support from other corporate sponsors in the beauty and fashion industries. Some companies have captured this enthusiasm for fund raising and have brought out their own pink products with a proportion of the profit on the goods going to charity. However, as well as highlighting inappropriate marketing, some breast cancer charities are sceptical about the motivations behind corporate sponsorship. For example, the charity Breast Cancer Action is critical of what they see as vested interests of corporate sponsors who they refer to as 'Pinkwashers'. They argue that although they may purport to care about breast cancer by promoting pink-ribboned products, they may also sell products which use or produce chemicals that have been linked to cancer (www.thinkbeforeyoupink.org accessed 1/9/12).

In this country, Asda started its 'Tickled Pink' campaign in 1996 to raise money and awareness of breast cancer. However, some people have expressed discomfort with the title of the campaign. For example, one message on the Breast Cancer Care website forum describes a visit to Asda where 'the message really was that BC was 'fun' and Tickled Pink really did mean very pleased! Felt like crying, which is

not like me AT ALL' (www.breastcancercare.com accessed 23/7/12). Discussing the success of breast cancer awareness and money-raising activities such as 'The Race for Life', chief executive of charity Breast Cancer Care Samia al Qadhi (2008) argues that pink unifies women in the common cause of raising consciousness about breast cancer and can engender a feeling of mutual support amongst women in the face of a common threat. However the focus on ultra-feminine pink products seems to contrast sharply with the actual experience of breast cancer treatment. Nevertheless, this is a prominent cultural message in the UK at the present time and is influential both to those affected by breast cancer and the people with whom they interact.

Sometimes military metaphors are combined with charities who use pink as a way of uniting women, as this advertisement illustrates:



http://www.bishopperowne.co.uk/images/race_for_life
[accessed 27/3/2012](#)

This adaptation of a famous war poster features the image of Lord Kitchener wearing a comedy pink wig. He is pointing directly at the viewer suggesting a moral imperative to 'join the girls', emphasising how women are (or should be) united in a common 'fight' against cancer. Moore (2008) however, argues that women should be angry at the association of illness with fluffy pink imagery. My participants' views on the subject will be discussed in chapter 7.

In the next section I outline the research questions that will guide the current study.

Research questions

The overarching research question is:

'What is the 'new normal' for women who have finished treatment for early-stage breast cancer or DCIS?'

The main aim of this research is to explore women's experiences after treatment for early-stage breast cancer (ESBC) or DCIS. What happens when the 'rollercoaster' of treatment is over? Is it possible to go back to 'normal'? Or do women find a 'new normal' as Mukherjee (2011b) suggests? If so, what does this new normal look like?

Bury's (1982) theory of chronic illness as a biographical disruption will be invoked in order to explore how women come to terms with being diagnosed with a life-threatening disease which may or may not reoccur. However, instead of concentrating on the emerging disease as Bury did, the current research will also focus on the period after hospital-based treatment has finished. I will therefore be expanding on Kaiser's (2008) interview study of the meaning of survivorship for 39 women who had completed treatment for breast cancer 3-18 months previously. Kaiser found that women often have contradictory feelings after successful treatment. Whilst her participants reported that they were grateful to have survived, they often still feared recurrence which made them uneasy at accepting the public perception of them as cancer survivors. The current study includes the narratives of women who were beyond the first two years of treatment and therefore offers new insights into the lived experience of women living with long-term consequences of treatment for ESBC/DCIS.

In addition to the overarching question, there are also four underlying questions:

1. 'How do narratives reveal the ways that women make sense of the biographical disruption caused by breast cancer?'

Riessman (1993) explains how narratives can provide the means for difficult experiences to be made meaningful by placing order on otherwise chaotic events. In cases of chronic illness, narratives provide a way of reconstructing a coherent sense of self. Having chosen to use a narrative method in my research, the narratives provided by my participants will be explored to uncover the nature of disruption to their lives, the meanings they ascribe to the experience and how they have dealt with the disruption. This may in turn reveal important links between individual experience, identity, and the wider social world.

2. 'How do women experience the end of intensive treatment?'

Unlike Bury's (1982) participants, and also unlike women diagnosed with secondary breast cancer, my participants were effectively cured after treatment. Their personal narratives will be analysed to explore the sometimes contradictory emotions expressed by the participants regarding this period. Does the cessation of treatment come as a relief, or can it also be experienced as a loss of a safety net, as Ward et al (1992) suggest, based on their study of 38 women six months after treatment completion?

3. 'What happens to a woman's identity when norms of femininity are disrupted by breast cancer and its treatments? How do women experience a 'new normal' body?'

Bury(1982) argues that previously taken for granted aspects of identity such as body and social roles are called into question by the experience of illness. However, Wilson (2007) in her study of mothers with HIV argues that Bury did not particularly consider gendered dimensions of biographical disruption, despite 25 of his sample of 30 participants being female. I aim to broaden this aspect to consider whether notions of the gendered self change in the experience of ESBC/DCIS and its afterlife. The current study will explore the way that gendered identities are affected by cancer and its treatments particularly in respect of dominant models of femininity and normative gendered heterosexual roles.

4. 'What are women's experiences of relationships during and after treatment for ESBC/DCIS?'

There are numerous studies of relationships during treatment for cancer (for example Kayser et al, 2007; Emslie et al, 2009) but fewer that look at what happens to those relationships once treatment ends. Because the interviews were conducted some time after treatment had ended, participants had chance to reflect on the differences between relationships at these two times and their feelings about it. This will further our understanding of the nature of 'new normal' relationships with a range of people in the aftermath of treatment for ESBC/DCIS.

Structure of the thesis

The thesis begins with a review of the current literature surrounding this topic and a discussion of the theoretical framework upon which the current research is based. This is followed by a chapter describing my methodology and the methods used in conducting the research. I describe how this research will be an interview based study which will give participants the chance to tell their story in their own words, starting from the time that they first suspected that they had breast cancer. I explain the motives for using a narrative approach and how the analysis will look at the narratives as a whole, as well as common themes that crop up within individual stories. The narrative approach situates the breast cancer experience within participants' lives and as such gives scope for alternative explanations which challenge the concept of illness as biographical disruption.

Following the literature review and methodology, there will be four data chapters which are arranged in a roughly chronological order. I have started by discussing the initial disruption of diagnosis, where the majority of the participants went from an assumption of health to entering into the sick role (Parsons 1951). In particular, in chapter 4 I have focused on the effects on identity of losing their hair, which is associated with the period of treatment. I then look at the period after intensive treatment has ended which reveals mixed feelings of relief and terror as well as presenting a chance to absorb what has actually happened. In chapter 5 this is compared to the state of liminality, as many participants cannot be classified as ill but neither do they feel that they are back to what they were before diagnosis. My

contention is that they never will be back to 'normal', particularly in view of the changes to their bodies resulting from treatment for ESBC/DCIS. The ways that women construct their 'new normal' in terms of their body and relationships are examined in the final two data chapters. The thesis ends with a chapter in which I will highlight the conclusions that have emerged through my analysis of the data. This will also be the space for discussing limitations of the research and recommendations for further study.

Chapter 2. Literature review

Introduction

In this chapter I will set out the theoretical frameworks upon which this research is based and position the research within the existing literature. This research fundamentally fits within the canon of literature relating to the sociology of health and illness. However, as this is such a wide field I will be concentrating on the strands of the literature which are of greatest significance to the current research. The chapter is in three sections starting with a discussion of the sick role as proposed by Parsons (1951). This provides the basis of studying illness as a social role, thus acknowledging the role of intersubjectivity in the experience of illness and recovery.

In the second section I discuss the way that illness, and particularly a sudden diagnosis of a life-threatening illness, can disrupt the healthy human life, drawing on Bury's (1982) concept of biographical disruption which provides the theoretical framework upon which this research is based. This will include a discussion of the aspects of Bury's theory which the current research expands upon; namely context, gender and the post-treatment period.

In the final section I will present the theoretical framework of liminality (Turner, 1969) as a means of exploring the post-treatment period. As was discussed in the introductory chapter, treatment for early-stage breast cancer is becoming increasingly effective and consequently, more women are living longer post-treatment (Cancer Research UK, 2012). This

has led to concerns about the nature of survivorship; therefore the focus of this study is the period after treatment has been completed, particularly aspects of the experience related to the body and relationships. I will therefore be building on Bury's (1982) concept of illness as biographical disruption by suggesting that moving out of the sick role can also be experienced as disruptive. In addition I will be combining the concepts of biographical disruption and liminality which will be the first time (to my knowledge) that they have been used for a study of a cancer that almost exclusively affects women. In the case of ESBC/DCIS the post-treatment period under examination can be characterised by an ongoing fear of recurrence and the sudden withdrawal of both medical and social support. This, combined with the long-term effects of treatment has led to oncologist Mukherjee (2011b) suggesting that life after cancer entails living with a 'new normal'.

Throughout this chapter, I will consider the gendered nature of biographical disruption, which critics argue was largely neglected in Bury's (1982) original study of rheumatoid arthritis. For example, Wilson (2007) notes that although 25 of Bury's participants were women, there is a lack of engagement with gendered aspects of biographical disruption, particularly motherhood. This is especially relevant for the current study because ESBC/DCIS almost exclusively affects women and also breasts are an important signifier of womanhood. Therefore, in addition to the effect on women's roles, the lasting impact on the body of treatments for ESBC/DCIS means that gender is an important consideration in this study.

Section 1: Illness as a social role with social consequences

More than half a century has passed since Parsons (1951) revealed his concept of the 'sick role' which was proposed as an alternative to the purely biomedical model of illness. Parsons (1951:430) argues that illness is biologically and socially defined as it constitutes disturbance to the functioning of both the biological system and the social system and involves 'motivated interactions of human beings.' Over 60 years later, the concept is still used and continues to inform research and debate. It is important to study the social impact of illness because it acknowledges social relationships including the way that ill people are treated by doctors as well as family, friends and wider society. According to Parsons (1951), the sick role has four key aspects:

1. Exemption from normal social role responsibilities, although this is relative to the nature and severity of the illness. This exemption requires legitimation, usually through a doctor who Parsons refers to as the legitimating agent. The legitimation of being sick enough to avoid obligations is not just a right of the sick person but also an obligation upon him [sic]. People are often resistant to admitting they are sick and it is not uncommon for others to tell them that they *ought* to stay in bed. Sickness generally has a moral connotation, consequently this legitimation has the social function of protection against 'malingering'.
2. The sick person cannot be expected by "pulling himself together" to get well by an act of decision or will. In this

sense also s/he is exempted from responsibility – s/he is in a condition that must 'be taken care of'. The condition must be changed, not merely their attitude. While the illness lasts s/he cannot "help it". This element in the definition of the state of illness is obviously crucial as a bridge to the acceptance of "help".

3. The state of being ill is undesirable; therefore there is an obligation to want to "get well". Legitimation of the sick role is only for the period of illness and is conditional on the person leaving this unfortunate state as expeditiously as possible.
4. The obligation – in proportion to the severity of the condition, of course – to seek *technically competent* help [a doctor] and to *cooperate* in the process of trying to get well. It is here that the role of the sick person as patient becomes articulated with that of the doctor in a complementary role structure (Parsons, 1951:436-437. Original emphasis).

As indicated above, a key aspect of the sick role theory is the proposal that normal roles and responsibilities are suspended until the person gets well. Consequently illness is described as deviant because people are unable to perform their social role and normal life functions (Young, 2004). Turner (1987) notes that it is commonplace in most societies for illness to be used as a reason for withdrawing from the social world, although he suggests a range of illnesses that do not fit the sick role definition. For example, epilepsy is a long term

illness which does not have the legitimation afforded by the sick role even though it may impact on social responsibilities such as driving. Turner (1987) also argues that the sick role does not take into account gender and class differences. For example, removal from work commitments is not an option for everyone because as Cockerham (2004) argues, some people are compelled to work through their illness because they have no other means of financial support, making the sick role theory less applicable to working class patients. And even though Parsons (1951) proposes that women carrying out unwaged work fall easily into the sick role, Radley (1994) suggests that they often have to 'fit in' the sick role around their normal duties, for example going to bed in between looking after children. In addition there are some people who do not want to withdraw from their normal role. For example Charmaz (1983) who interviewed 57 people with chronic illness argues that people will often devote their energy to attempting to carry on working. This is not just for financial reasons but also because of the impact on their self concept when they felt unable to perform everyday routines.

Parsons (1951) highlights the fact that the sick role can encompass anybody, regardless of their status in other areas of their life. When illness removes people from their working role this can affect their identity. Scambler (2008) argues that illness assumes 'master status' so that people become known by their illness first and by their occupational, social or family role second. For example, Kolker (1996) describes how, following her diagnosis of breast cancer, she felt she was no longer identified as an academic, and reflects that it was a short journey from professor to patient. Bury (1982) describes this as being 'taken over' by a disease. This is an indication of

how identity is affected by entering into the sick role. However I will argue that for the participants of the current study, this is a temporary change. Once treatment is completed they leave the sick role, yet for reasons that I will discuss later in the chapter, they do not revert to their pre-illness state but enter a state of liminality (Turner, 1969).

The sick role not only affords certain rights for ill people, it comes with obligations. In the context of cancer, these obligations also encompass the expectations that society has of ill people. For example in chapter 1 I discussed the proliferation of military metaphors employed by both the media and in medical settings which refer to people 'battling' cancer and putting up a fight. Similarly, an emphasis on pink positivity in breast cancer awareness campaigns contributes to culturally appropriate responses to illness such as stressing the need to maintain a positive attitude. Consequently, people affected by cancer are stuck between these expectations of behaviour and the reality of their feelings which may be wildly disparate. This in turn can impact on their relationships with other people, as will be discussed in chapter 7.

Whilst most people have a desire to get well, Parsons (1951) suggests that some people may find the sick role an attractive proposition as a means of gaining some privileges and simultaneously avoiding responsibilities. However, Scambler (2008) argues that this assumes that people are suffering from an illness where recovery is a possibility. This again disqualifies people with a chronic illness, as does the expectation that the patient will get well as soon as possible. In this respect, Crossley (1998) asserts that the definition of the sick role is more suited to temporary illnesses. In response to such criticism, Parsons modified his theory in 1975 to say

that the equivalence for wanting to get better is a desire to manage their illness. In the current study, management of illness entailed participants disguising the effects of illness and treatment such as hair loss and surgery to their breast(s). How and why they do this will be discussed later in this chapter in relation to Goffman's (1963) theory of stigma, along with a consideration of the consequences of normalization.

Section 2: Biographical disruption

The previous section discussed the limitations of the sick role theorisation in terms of explaining the impact of illness on people who do not have a temporary illness from which a full recovery is possible. In order to address this, Bury (1982) offers a new perspective in the study of chronic illness, proposing that it causes major disruption to the structures of everyday life and the knowledge that underpins them, akin to what Giddens (1991) calls a 'critical situation'. In a much-cited landmark study, Bury (1982) interviewed twenty five women and five men who had been recently diagnosed with rheumatoid arthritis. Newly diagnosed patients were selected in order to explore the disruption that can be caused by a diagnosis of a chronic illness. Bury (1982) describes three areas of biographical disruption which the sometimes 'profound shock' of a diagnosis of a chronic illness can bring about:

- i. Taken for granted assumptions and behaviours involving attention to bodily states;
- ii. Explanatory systems, involving a fundamental rethinking of biography and self concept;

- iii. Response, including mobilising resources.

Bury's (1982) theory relates to the current study because many of my participants reported that the diagnosis of ESBC/DCIS was totally unexpected. They had previously considered themselves to be healthy and also many felt that they were too young to be suffering from a disease associated with older women; findings which are echoed in Bury's study. According to Janoff-Bulman (1992) a diagnosis of illness can shatter previously held assumptions of indestructibility and security. This is illustrated by Stacey (1997), describing her reaction to her own cancer diagnosis:

'life, it has turned out, was not what it seemed...my 'healthy' body hosted a deadly disease'. (1997:5-6)

The shock of diagnosis which can seriously disrupt the assumption of being healthy as Stacey (and Bury) describes, has been discussed in the trauma literature. For example Green et al (1997) surveyed 160 women and found that a diagnosis of breast cancer is often experienced as a devastating trauma leaving the patient feeling frightened, vulnerable and out of control. In contrast to single traumatic events however, Stanton & Snider (1993) describe how breast cancer is sometimes experienced as a series of traumatic incidents due to the rapidity of the process of detection, diagnosis, decision- making and treatment in an atmosphere of heightened emotions. Consequently it is often not until the intensive period of treatment has ceased that women have the opportunity to reflect on what has happened. Cordova et al (2007) detail a number of psychological studies measuring distress levels of women who had completed treatment for

breast cancer which found evidence of post traumatic stress disorder (PTSD). However, in a recent review of 24 studies measuring PTSD and post-traumatic growth (PTG) in women with breast cancer, Koutrouli et al (2012) reported very few instances of PTSD whereas the majority experienced PTG. This suggests that many women have adjusted in a more positive way to their experience viewing it as an opportunity for reappraisal. In chapter 4 I will discuss the various reactions and responses to their diagnosis that were reported by my participants. Whilst some confirmed the shocking aspects of diagnosis this was not always the case, as will be revealed. Nevertheless, biographical disruption is relevant to the current study because although there are marked differences between the illnesses being studied, they similarly impact on multiple aspects of participants' lives. The current research examined narratives of women between 6 months and 29 years post-treatment and offers an opportunity to explore initial reactions to diagnosis as well as long-term consequences.

Meaning

Part of Bury's (1982) theory of biographical disruption is that it encompasses a search for meaning. Frankl (1959) believes that humans are motivated to find meaning in an experience and that this can transform a tragedy into achievement. He gives the example of cancer as a situation that a person cannot change; therefore the person must change themselves. Carricaburu & Pierret (1995) who used Bury's theory of biographical disruption in their study of men affected by HIV, argue that the interpretation of the illness experience is reflected in the consequences it has on the ill person's everyday life. According to Bury (1982), meaning as

consequence relates to how disruptive it is to a person's life and self-concept. This will be examined further in chapters 6 and 7 in respect of the consequences of ESBC/DCIS reported by my participants.

Bury (1982) argues that the disruption caused by illness to people's anticipated life trajectory inevitably leads to questions such as 'why me?' or 'why now?' Sontag (1991:39) adds that 'why me?' is a common response for people who learn that they have cancer where it can also mean 'it's not fair'.

Although some people are able to think of a possible medical explanation such as an inherited susceptibility, in an illness like cancer where the aetiology is rife with uncertainty, the search for meaning encompasses possible moral reasons as well as biological reasons. For example, Arthur Frank, reflecting on his own experience of testicular cancer, admits that he: 'could not resist asking "why me?" And this question led me to a sense of past inadequacy.' (Frank, 2002:86).

This overlap between scientific and lay explanations is illustrated by Hunt (1998) who carried out an ethnographic study of women in hospital-based breast cancer care in Mexico. She found that women attributed not only physiological reasons but also moral causes for their cancer, looking at past life events in the search to attribute meaning to an otherwise arbitrary occurrence. Similarly, Winnow (1992, p.74) describes how some people ascribe their illness to 'faulty spirituality,' feeling that God or karma is punishing them for some past mistake. In chapter 4 there will be a discussion of how the participants of the current study have made sense of what has happened, which Bury (1982) refers to as meaning as significance.

The current study is interested in the meanings that women find in their breast cancer experience both in terms of consequence and significance because as Bury (1982) argues, the meaning attributed to illness shapes the way it is dealt with in everyday life. Clearly, both types of meaning are dependent on the context of illness within people's lives. This was highlighted by Simon Williams (2000) who argues that illness as a biographical disruption cannot be sustained as a concept without consideration of the meaning, context and timing of illness within people's biographies. For example Harris's (2009) study of people's experiences of hepatitis C uncovered stories that troubled Bury's (1982) concept of biographical disruption. Harris argued that for half of her 40 participants, being diagnosed with hepatitis C was described as 'no big deal', sometimes because it was seen as an inevitable consequence of their history of drug-use. Williams (2000) argues that in such cases, illness does not represent a biographical disruption but is more accurately described as biographical continuity. For some of Harris's other participants, the diagnosis was of lesser significance than other traumatic incidents and was 'lost in a sea of multiple disruptions' (Harris, 2009:1036). Similar examples were found in the current study where some of my participants' narratives reveal that illness is not always experienced as 'shattering' due to the circumstances in which it occurs. The narrative approach of both Harris's study, and the current one, enables the illness experience to be contextualized and challenges assumptions of homogenous reactions to illness.

In some instances, previous life events are perceived to be inextricably linked to the onset of illness. For example, Taylor et al (1984) interviewed 78 women who were between one

and 60 months post-treatment for breast cancer along with their significant others. They found that 95% of the patients and 63% of their significant others had theories about the cause of the cancer, with the majority attributing it to 'stress'. They found that women had worse adjustment when they blamed a specific stressor which was individual to each woman. Unfortunately the nature of the study meant that there was no information about the nature of the specific stressor. However the qualitative approach employed in the current study facilitates the capture of this type of information more effectively which may help to provide a greater understanding of the context. In some cases previous traumatic events or stressful lives were suspected to have contributed to the onset of ESBC/DCIS. In these cases Simon Williams (2000) claims that this is best described as biographical disruption as chronic illness rather than the other way round. However, an alternative explanation is suggested by Gareth Williams (1984) who argues that such explanations are 'narrative reconstructions' which are used to place order on lives that have been disrupted by chronic illness.

The additions to Bury's (1982) original concept of biographical disruption are important to the current research because rather than looking at an emerging disease as Bury did, I will be asking women about experiences which happened some time previously. These retrospective accounts will place their experience of ESBC/DCIS within the context of their life story. Consequently, this may mean that biographical disruption may result from previous or even subsequent events. Therefore, rather than being limited in our understanding of illness as disruptive, Williams' (2000) theories of biographic continuity

and biographical disruption as chronic illness may be equally relevant in exploring the experience of ESBC/DCIS.

Biographical disruption and gender

Wilson's (2007) study of the effect of HIV infection on women's identities as mothers highlights a lack of engagement with the gendered aspects of biographical disruption in Bury's (1982) study, specifically the issue of caring responsibilities. Despite there being a majority of young women in Bury's sample, some of whom were mothers, Wilson argues that Bury over-emphasised work roles. However Bury (1982) did describe how mobilisation of resources includes a re-evaluation of social relationships which may require re-defining in terms of reciprocity. For example Dow and Lafferty (2000) interviewed 23 young women with breast cancer and found that they may have to rely on extended family to help with childcare during treatment which can alter family dynamics. Similarly, Charmaz (1983) describes how many chronically ill people fear becoming a burden to loved ones. For women who are traditionally care-givers, this disruption of their role can affect their sense of self, particularly where other facets of identity such as career are disrupted. However, Wilson's (2007) study and a more recent study of motherhood in the context of living with breast cancer (Fisher & O'Connor, 2012) suggest that despite the threat of disruption posed by illness, paradoxically their participants experienced biographical reinforcement to their identities as mothers. Both studies argue that maintaining normality helped women to have a biographical continuity, as well as minimising the disruption to their children's routines. As nine of the participants in the current study had children living at home at

the time of diagnosis, this is an aspect of the experience which may similarly provide a continuation of an aspect of their identity, when other parts of their lives (for example professional identity) are disrupted.

As well as affecting their roles within the home, the effect of gender on interpersonal relationships is also a consideration. Hochschild (2003) argues that because in our culture women are traditionally seen as the ones who care for others, women perform 'emotional labour' by disguising their true emotions for the sake of other people. Hochschild's concept was developed in relation to the emotional labour involved in customer focussed industries such as airline stewards. This is because people (generally women) in these positions are required as part of their employment to project a certain emotion to help other people to enjoy their flight etcetera. In the context of the current research I argue that some of my participants perform emotional labour to project a positive image both during and after their treatment (see chapter 7).

A gendered consideration of illness is inevitable when the site of treatment is the breasts which are an intrinsic aspect of womanhood. Moore (2008) argues that the cultural symbolism of the breast with its sexual and maternal associations means that breast cancer presents a particular challenge to assumptions of femininity and identity because the body is altered by the effects of drugs, radiotherapy and surgery. Therefore embodied experiences resulting from treatment for ESBC/DCIS can threaten to disrupt women's identities, self-confidence and intimate relationships and can make a return to the pre-illness state problematic. This is supported by a number of studies including Bredin et al (1999), Hefferon et al (2009), McCann et al (2010) and Thomas-Maclean (2005),

who argue that losing a breast is a complex experience but one that often challenges femininity and identity. Feelings of gratitude to be alive are mixed with anger and distress, along with guilt for feeling that way. Combining the theoretical concepts of biographical disruption and embodiment in their longitudinal study of 12 women during the first year following diagnosis of breast cancer, McCann et al (2010) argue that embodiment takes into account the impact of body changes resulting from treatment. In interviews conducted at three time points (after diagnosis, during treatment and at a follow-up appointment) their participants described how changes in their appearance had implications for identity, and that an altered body led to an altered sense of self. Of significance to the current study is the effect of permanent body changes where the implications of surgery are often not felt until the initial shock and the intensive treatment has ceased. Unlike McCann et al's (2010) study, only three of my participants were interviewed within twelve months following their diagnosis. Therefore the current research offers a unique understanding of the long-term consequences of treatment for ESBC/DCIS. Most (19) participants were between 2 and 9 years post-treatment, and the remaining three had first been treated 16, 19 and 29 years ago, respectively. Therefore it offered the opportunity to explore the nature of embodied and biographical disruption beyond one year after diagnosis including permanent bodily changes resulting from treatment for ESBC/DCIS. Of interest will be whether they can accept their new body or whether scars and an altered body shape act as embodied reminders of the trauma they have been through as former cancer patient Stacey (1997:100) suggests:

'Bodily memories are lingering spectres of the trauma of having cancer, surgery and chemotherapy'.

These embodied changes are discussed in chapter 6 in terms of living with a new normal body. For example, after treatment, Potts (2000:122) describes surgical scars, reconstructed breasts and tattooed radiotherapy targets as 'cultural inscriptions on the body' which challenge the sense of wholeness and symmetry traditionally associated with beauty. Thomas-Maclean (2004) points out that such physical reminders make it hard for women to retain their pre-cancer self-perception and therefore they may need to accept bodily changes. Bredin et al (1999) claim that their qualitative study which used a combination of therapeutic massage and in-depth interviews, uncovered a deep understanding of the trauma attached to women's experiences of breast loss. Unfortunately only three women were interviewed but findings suggest that many women may be concealing the anxieties they live with in a changed body, in a similar way to their concealment of the effects of mastectomy. Conflicting emotions, specifically the repression of anger and distress at the loss of their breast(s) were sidelined because of a perceived need to express gratitude at being alive. Bredin et al (1999:1119) argue that massage 'allowed significant disturbing experiences and feelings to be talked about..in a way that went beyond words', suggesting that alternative means of exploring women's experiences may be helpful. Other studies have explored different ways of facilitating meaning-making for women with breast cancer such as one where two women had plaster casts made of their post-mastectomy torsos. Sabo & Thibeault (2012:204) argue that this helped the participants to reconstruct and reclaim their

identities as women, as well as to 'generate meaning out of the chaos of cancer'; although they admit that both participants entered the study with a positive self-image. Although both of these studies are extremely small scale even by the standards of qualitative research, nevertheless they highlight the importance of considering all aspects of women's experiences and facilitating meaning-making wherever possible. The narrative approach of the current study (which has 24 participants) encourages this. This will be discussed in chapter 6 which considers the role of the body as women negotiate their 'new normal' which in some cases includes measures to avoid stigmatization, as will now be discussed.

Stigma

Following Parsons' (1951) assertion that sickness is socially undesirable, Radley (1994) argues that people with chronic illness who reject the sick role must manage their symptoms in order to avoid stigma and be accepted by the healthy population with whom they spend most of their time. The necessity of managing illness is informed by Goffman's (1963) theory of stigma, which he defines as 'the situation of the individual who is disqualified from full social acceptance' (1963:9). Peters-Golden (1982) compared the views expressed by 100 breast cancer patients with those of 100 'healthy' individuals (both male and female) and found that the breast cancer patients reported that sometimes friends or family members avoided them. This was reinforced by the healthy individuals who admitted that they often avoided people with cancer because it increased their own sense of vulnerability to death and dying. Scambler (2008) describes two forms of stigma:

- i. Enacted – where people suffer discrimination based on their appearance;
- ii. Felt – feelings of shame and fear of discrimination.

The fear of stigma can motivate people to try to conceal their illness by trying to normalise their appearance. This may be because, as Bury (1982) suggests, deviating from appropriate norms of appearance and behaviour can have disadvantages. Giddens (1991:58) adds that a person's 'ontological security' is threatened by personal crises by which he means that people are required to maintain their normal appearance in order to enable life to continue as usual and preserve social acceptability. For example, Carricaburu & Pierret 's(1995) study of 44 asymptomatic HIV-positive men and Gray et al's (2000) study of men with prostate cancer found that participants reported that they concealed their health status wherever possible. They chose whether to disclose their condition on a 'need to know' basis so as to avoid invoking pity, being treated differently or suffering social exclusion. In the current study, this was an option for participants once their hair had grown back and their outward appearance had been restored through surgery or use of prostheses. Normalisation meant that they were able to choose whether to reveal their cancer status although this was not always straightforward, as will be discussed in chapter 7.

Stacey (1997), suggests that the rituals of secrecy and disguise become part of living with a stigmatized disease although trying to maintain taken for granted aspects of life requires careful planning. For women who are undergoing treatment for cancer this is aided by the 'look good feel better'

project which is a service sponsored by cosmetics firms and aims to help women disguise the effects of treatment through use of make-up and wigs. In a critique of such projects, Kendrick (2008), argues that concentrating effort on the individual to disguise the effects of treatment, does nothing to challenge the stigma of cancer. Instead, she sees it as a reinforcement of cultural norms of what constitutes a healthy woman and propagates ableist and heterosexist discourses. Similarly, some treatments for breast cancer have been criticised by feminists for the emphasis on normalizing women's appearance and sexuality even though these may not be in the best interests of the women themselves. For example, in a feminist critique of the advice and treatment given to women with breast cancer, Wilkinson & Kitzinger (1993) suggest that the male-dominated medical sphere is reflected in treatments such as breast reconstruction. They argue that it is routinely offered to women because of male assumptions that restoring femininity and sexuality is of uppermost importance. This is despite the fact that reconstruction involves major surgery to the back or abdomen and sometimes to the remaining healthy breast in order to achieve 'a good match.' Wilkinson & Kitzinger argue that rather than restoring body shape, most women's actual priority is their health and survival. Nevertheless they claim to have found numerous examples in the literature where women have felt pressurised to conform with norms of appearance (e.g. Johnson, 1987 cited in Wilkinson & Kitzinger, (1993). Several interview studies have explored women's feelings towards mastectomy and reconstruction. Kasper (1994) argues that as well as being life-threatening, a diagnosis of breast cancer disrupts a woman's physical integrity and can reveal taken for granted assumptions about

what a 'normal' woman looks like. Kasper (1994) therefore believes that it is only by placing women at the centre of an enquiry (as the current study does), that we can learn how the everyday lives of women are connected to the dominant social order. More recently, Fallbjork et al (2012) reported reactions to mastectomy ranging from 'no big deal' to 'losing oneself'. Beesley (2012) found that women's opinions of their reconstructed breasts were linked to how the breasts felt. Consequently the cosmetic appearance of the breast was not of utmost importance to them, whereas this was emphasised by clinicians. Each of these qualitative studies underlines the importance of considering individual cases. The feminist narrative approach of the current study provides space for these complex and often contradictory emotions surrounding the loss and reconstruction of breasts to be explored. As Sabo & Thibeault (2012:209) argue: 'the ability to successfully cope with the stress of breast cancer appears to be associated with how women relate to their own bodies as well as how they relate to others'. These issues which centre on the theme of normality will be discussed in chapter 6.

In her breast cancer diaries, Lorde (1980) criticises 'normalization' because she believes that it makes women with breast cancer 'invisible' and therefore powerless because they cannot be political if they are unable to identify each other. I would add that neither can they offer social support to each other. Bury (1982) proposes that the presence or absence of a supportive social network has a profound effect on the illness experience. The role of social support has been well-documented in studies of breast cancer patients where the consensus seems to be that women who receive

appropriate support tend to cope better. Indeed, a recent study by Chou et al (2012) of 584 American patients over 12 years post treatment, argues that women's chances of surviving breast cancer are improved where there is good social support since it can enhance coping skills. Conversely, an American study by Allen et al (2009), based on data from focus-groups of 47 breast cancer survivors, found that participants reported struggling to cope with family, work and social responsibilities once they finished treatment because this coincided with a loss of social support. In the current research, the participants' experiences of social support (both practical and emotional) will be explored in terms of their relationships both during and after treatment and will be discussed in chapter 7. Additionally it seems that the source of this support is important. For example, after treatment the special understanding shared with other cancer patients seems particularly pertinent. In interview studies, Dakof & Taylor (1990) and Dunn & Steginga (2000) found that peer support was most helpful. For example, one woman said 'You know, all you got to do is tell another breast cancer patient "My check-up is in 3 days" and we all know what that experience is like'(Dakof & Taylor, 1990:85). In the current study the majority of my participants reported that they had access to a breast cancer support group as well as online support through various charities such as Breast Cancer Care. However Vickberg (2001) cautions that peer support should not be unilaterally accepted as beneficial. She reports that several of the women she interviewed were influenced by interactions with other cancer sufferers, and specifically that being around other people with cancer increased or triggered their fears of recurrence. However, the focus of Vickberg's study was women's fears of breast cancer recurrence;

therefore her participants may not have discussed the more helpful input of other women who had been affected by breast cancer. In chapter 7 I will discuss the extent to which peer support is helpful based on experiences that were reported by my participants. This may offer an insight into the types of support that are most useful for women during and after treatment for ESBC/DCIS.

Section 3: Biographical disruption and the end of treatment

The post-treatment period becomes relevant to the current study because of its focus on ESBC/DCIS which is deemed to have been effectively treated. Although Bury (1982) discusses the disruption caused when a person becomes a patient, I will argue that further disruptions occur after treatment has ended and that this can be a time of crisis. This is a crucial contribution of my theorisation of women's post cancer lives. Bury's (1982) concept of chronic illness as biographical disruption was based on his study of 30 people who were interviewed about their experiences of coming to terms with a diagnosis of rheumatoid arthritis (RA). Whilst there are similarities between Bury's study and the current study, there are also marked differences due to the nature of the illnesses under discussion. RA has a gradual onset and progressive worsening of symptoms, whereas many of the participants of the current study remarked how they had no symptoms other than a lump or none at all and had only found out as a result of breast screening. RA is not terminal but neither is it curable therefore patients must learn to live with an increasing

amount of pain and disability. ESBC/DCIS on the other hand is treatable and once treatment ends people are no longer perceived to be ill. However breast cancer has a risk of recurrence, either in the same or other breast, or as secondary cancer (metastasis) in another part of the body which would be incurable. This research considers women who have had successful curative treatment for ESBC/DCIS and therefore they no longer fit the sick role definition in Parson's (1951) sense. However, the fear of recurrence means that for many women, the illness experience goes beyond the conclusion of treatment, a suggestion that is reinforced by social psychologist Radley (1994) who asserts that the uncertainty surrounding the causes of cancer can increase the fear that it may return. Radley therefore suggests that the prospects of a definitive recovery are 'limited at best'. For example Stacey (1997), drawing on her own experience of cancer reflects:

'once diagnosed, death becomes part of life and refuses to be banished. It becomes a constant companion. A new certainty. The only certainty.' (Stacey, 1997:73)

This ongoing fear is confirmed empirically by Vickberg (2001, 2003) who interviewed 16 women and surveyed 169 more and found that over half of her participants expressed moderate to strong fears about recurrence of breast cancer. Younger women were more fearful of recurrence which Vickberg suggests may be due to the unexpected nature of receiving the initial diagnosis at such an early stage in their life.

Vickberg's study was one of the first to ask women about the nature of their fears as well as the triggers for the fears and the way they cope on a day-to-day basis. It may be this fear

of recurrence that contributes to feelings of unease at the end of treatment as will now be discussed.

End of treatment as crisis

Whilst considering biographical disruption in terms of the transition from a perception of being previously healthy to being diagnosed with a serious illness, it seems that sometimes the cessation of active treatment can be as disruptive as the diagnosis. My participants reported that when treatment ended they stopped having the rights and responsibilities associated with the sick role as described by Parsons (1951). However, unlike a condition such as a broken leg where there is generally relief that treatment has ended and people can attempt to resume their 'normal' lives, the post-treatment period for women with ESBC/DCIS can be experienced as a time of distress, confusion and ambiguity. Arnold (1999) who questioned people after cancer treatment had finished argues that the cessation of cancer treatment can represent a crisis to some people. As noted previously, the sick role requires patients to comply with doctors. However, when treatment ended Arnold found that some of her participants reported that they were still emotionally reliant on doctors, which led to feelings of abandonment. This can be seen in the present study when, after several months of intense medical attention, the frequency of medical check-ups is reduced. Typically they go from 6 months to a year and after 5 years there are no check-ups for 3 years (or none at all for younger women who must wait until they are 50 to enter the system of 3 yearly checkups). Once medical checkups have ceased many women report feeling isolated and vulnerable and some experience this as a rejection.

In this respect, it could be argued that the cessation of treatment is often where women's struggles begin. Ward et al (1992) surveyed 38 women before, during and after treatment for breast cancer about their reactions to completing therapy. The findings reveal that, although they were pleased to have finished, 30% of them were distressed by the termination of their treatment and lamented what they saw as a loss of their 'safety net', which increased their sense of vulnerability. Interestingly, women expressed relief at being asked about their reaction to ceasing therapy as it reassured them that it is not unusual to be upset about it. This is in contrast to most illnesses where people are glad to finish treatment. My research therefore builds on Bury's (1982) concept by suggesting that further disruption may occur at the end of intensive treatment. Ideas about recovery from illness are complicated by my findings which indicate that the end of treatment does not mean a return to a pre-illness state. Rather, it can be a time when further difficulties may arise due to fear of recurrence and a perceived loss of both medical and social support. This has led to research that suggests an ongoing need for support such as Boehmke & Dickerson (2006) who argue that based on secondary analysis of interviews with thirty women who were about to finish active treatment for breast cancer, there is a need for care long after formal treatment ceases. Similarly, from their point of view as health professionals, Tighe et al (2011) argue that women need support during the transition from treatment to a 'normal' life. They interviewed 10 women four times over the first year following diagnosis of breast cancer and highlight the lack of support in helping women to cope with the effects of

treatment on their bodies and relationships. However, these studies seem to suggest that addressing the lifelong consequences of breast cancer treatment would enable women to live 'normal' lives whereas the contention of the current research is that in this post-treatment, post trauma period, women must negotiate a 'new normal' (Mukherjee, 2011b:27) both in terms of their body and their relationships. The implications of this will be the subject of the final two data chapters.

It seems therefore that the post-treatment period is the time when women may find themselves renegotiating their biographies that have been ruptured by the illness experience. Although the post-treatment period for women with breast cancer has been the subject of previous research (e.g. Silva & Santos 2010, Stanton 2012, Tighe et al, 2011) I believe that the current research is the first to do so using the theoretical concepts of biographical disruption and liminality. As will be seen in the next section (and more comprehensively in chapter 5), there are striking similarities between the situation reported by my participants during treatment and its aftermath, and the liminal state as described in anthropology (Turner, 1969).

Liminality

The term liminality from the Latin 'limin', meaning threshold, (*Oxford English Dictionary* 2011), is used in social anthropology to describe the transitional period between leaving one state but not yet entering a new one. In his seminal work, *The Ritual Process*, Victor Turner (1969) takes

the term first used by Arnold van Gennep in 1909 to describe a phase of rites of passage. This is part of a three-phase process where the subject is separated from his/her place in the social structure and finally is reincorporated into it. Turner (1969) describes various tribal rituals where the purpose is to reduce subjects to their lowest ebb by means of stripping them of wealth and power and subjecting them to physiological pain and humiliation that they are forced to submit to without complaint. He explains that the reasoning behind this treatment is that subjects can only be great leaders if they have also have had experience of having nothing. It is the transitional period where people have been stripped of wealth and power and have not yet reintegrated into society that Turner refers to as the liminal state.

Turner (1969:95) argues that this liminal state is characterised by anonymity, sexual continence, passivity, invisibility, silence and ambiguity, as subjects find themselves 'betwixt and between' states in which they can be easily classified. This understanding of liminality as ambiguous, powerless, and silent can offer new insights into the liminal state of the participants in the current study, as similar traits are evident within the narratives of women who have been treated for ESBC or DCIS. They are often unable to describe themselves as either ill or healthy but also report a perceived lack of agency in many areas of their lives, as a result of what they have been through.

As well as defining a state as 'any type of stable or recurrent condition that is culturally recognised' such as legal or married

status, Turner (1969:94, 1967) also relates the term to physical conditions such as describing someone as being in a certain state of health. Rather than being in a particular state of either health or illness, the participants in the current study are in transition; 'no longer classified and not yet classified' (Turner, 1967:96). The participants have left the state of being ill with the rights and responsibilities of the sick role (Parsons, 1951) but are not yet, and may never be, in a clearly defined state of health. Not only does early stage breast cancer carry a risk of possible recurrence but also treatments are lengthy and monitoring continues for the rest of the lives of those affected. Cancer specialist Mukherjee (2011b) describes how a breast cancer patient may have surgery, chemotherapy and radiotherapy followed by hormone treatment, thus extending the illness duration for five to ten years and possibly to the next generation as her daughters and granddaughters may be genetically tested. In the present study, all except one of the participants had completed intensive treatment for breast cancer (surgery and/or radiotherapy/chemotherapy). Some of them were still having hormone treatment, usually in the form of daily tablets for five years and some were waiting for plastic surgery to reconstruct breast(s) that had been removed some time previously.

Liminality in other contexts

Whilst Turner established the notion of liminality with respect to tribal rituals, he also argued that all of these characteristics can equally apply to people in other societies. For example, religious contexts such as monasteries display similar attributes as subjects are required to eschew material wealth, observe silence and be sexually continent. Turner also talks

about communities of liminal people which he calls 'communitas' on the fringes of society. In Turner's case, he relates it to the rebellious youth of the 1960's when he was writing, namely hippies and teenyboppers who, he argues, 'opt out of the status-bound social order' (Turner, 1969:112).

Since then, the term has been adopted widely and used in various other contexts such as in business studies (eg Beech (2011) who applied it to human relations in businesses) and literary criticism as well as sociology. For example, Ramphele (1997) describes the situation of South African widows as liminal. She observed that despite being no longer effectively married, in that particular culture widows are still associated with their deceased husband. Therefore she argues that these women are in an ambiguous liminal state of being neither married nor single. The concept of liminality can also be applied to the illness experience because during the transition, the subject enters a period which has the attributes of neither the previous nor the coming state. In the current context it can be likened to being on the borders of what Sontag (1990:3) refers to as the 'kingdom of the well and the kingdom of the sick.' Sontag argues that we all have citizenship of both kingdoms and whilst we prefer to dwell in the former, sooner or later we spend time in the kingdom of the ill. The experiences of the participants in the current study blur the boundaries of these two kingdoms.

Liminality has been a common theme within health and illness literature since Little et al (1998) introduced the idea that some aspects of the experience of cancer could be likened to

the liminal state described in social anthropology. In their much-cited study of ten patients undergoing treatment for bowel cancer, Little et al argue that cancer is experienced as liminal because patients feel unable to be classified as either ill or well. They argue that liminality starts at diagnosis and continues for the rest of a person's life and has three distinctive characteristics:

1. Impact of diagnosis and henceforth an identity as cancer patient;
2. Communicative alienation where people feel unable to communicate their experience to others who have not been through similar events;
3. 'Boundedness' where people feel constrained in terms of time, power and space as a result of their illness (Little et al, 1998:1486).

Since Little et al's study, there have been several studies that have conceptualized illness experiences in terms of liminality. For example, Forss et al (2004) applied liminality to describe the uncertainty felt by 30 women whose smear tests revealed cervical cellular changes. During interviews the women described in their own words how they had expected to be confirmed as healthy but the notification of an abnormal smear test took them from a state of assumed health into a state of ambivalence which Forss et al describe as liminality. In contrast to these studies, the current study contextualised diagnosis within participants' biographies and as I will explain in the following section, I have used the concepts of both

liminality and biographical disruption for the first time in a study of women's experiences of ESBC/DCIS.

Liminality as a biographical disruption

Parallels can be drawn between the work of sociologist Bury (1982) in relation to biographical disruption and anthropologist Turner (1967, 1969) in relation to liminality. Both argue that in certain circumstances previously taken for granted norms and values of the structures of everyday life are revealed. For Bury it occurs when people are removed from their former state as a result of illness, whereas for Turner these disclosures take place when subjects are in a state of liminality. Turner argues that when people are withdrawn from their former positions in society, they are forced to think about 'persons, relationships and features of their environment they have hitherto taken for granted' (Turner, 1967:105). When applied to illness, this also includes previously taken for granted bodily states.

The connection between biographical disruption and liminality has been made in previous studies such as Navon & Morag (2004) and Cayless et al (2010) who drew on both these concepts to analyse the experiences of men who have been treated for prostate cancer. Navon & Morag (2004:2344) interviewed fifteen men and reported that hormone treatment seemed to have left men bereft of the necessary attributes for 'health, love, maleness and meaningful marital and social ties'. They argue that post-treatment relationships were unclassifiable as the participants' identities were disrupted to the extent that they no longer felt as they once were but also

felt unable to construct an alternative self (Turner, 1969). Navon & Morag (2004) argue that these circumstances subjected the participants to a state of liminality because they could not be classified as either normal or abnormal. Cayless et al (2010) extended Navon & Morag's work by considering the strategies employed by men with prostate cancer to manage the ambiguity and uncertainty associated with the liminal state. They found that side effects of the treatments such as incontinence and impotence posed a major threat to the men's physical identity, and in addition they experienced disruption to intimate and social relationships as well as to future plans. In order to consider liminality as biographical disruption, Cayless et al (2010) argue that it is necessary to capture experiences over time. Therefore they interviewed participants three times over a year at what they saw as critical times in the illness trajectory namely diagnosis, treatment and follow-up. This strengthened the study since it meant that experiences were captured over time. However, it also restricted their data to the events of one year during which participants were being medically monitored. As mentioned previously, the current research suggests that further disruption occurs once intensive treatment for ESBC/DCIS has finished. However, Cayless et al (2010) argue that biographical disruption should be understood not only in terms of illness, but also the aftermath of treatment which can be experienced as liminality. This is equally applicable in the current study although in this case the focus will be on women's experiences, specifically in terms of the effects of treatments for ESBC/DCIS on their bodies and relationships. It therefore builds on previous research because although taking elements from these prior studies in respect of disruption to bodies (Little et al, 1998) and relationships (Cayless et al,

2010, Navon & Morag, 2004), there are crucial gendered aspects to my study. Along with possible disruption to femininity and sexuality resulting from breast surgery, there may also be disruption to a wide range of relationships, not just intimate ones. I therefore argue that the current study is unique because it relates liminality and biographical disruption specifically to women's experiences of ESBC/DCIS whereas previously these concepts have only been used in connection with male cancers. Therefore this study will extend our understanding of the post-treatment experience and specifically offers a gendered consideration of both liminality and biographical disruption.

Chapter summary

This literature review has brought together strands of literature from different disciplines in order to explore the complexity of the experience of living with and beyond ESBC/DCIS for women in today's society. The impact of having a life-threatening disease on a woman's perception of herself and her life is best understood in relation to Bury's (1982) theory of illness as biographical disruption which underlines the importance of attaching meaning to the experience. This will be examined in the current study using a feminist perspective on this gendered experience.

The review in this chapter has followed the trajectory of illness, looking firstly at the disruption caused by entry into the sick role (Parsons, 1951) with its associated rights and obligations. This will be further explored analytically in chapter 4. It then moved to consider the post treatment period which has

specific challenges in respect of the experience of having had ESBC/DCIS. The complex experiences encountered during this time will be explored in chapter 5 using the concept of liminality (Turner, 1969). I have described how the concepts of liminality and biographical disruption have both been drawn upon in order to explore the uncertainty and ambiguity following the cessation of treatments for ESBC/DCIS. I believe that this is the first time that they have been combined to study a cancer that mainly affects women and therefore facilitates a gendered discussion of the implications of treatment for ESBC/DCIS for women's bodies and relationships which feature in Chapters 6 and 7 respectively.

Overall, the current study challenges existing theoretical ideas of recovery in the face of a life-threatening experience. As well as permanent bodily changes resulting from surgery, the ongoing possibility of recurrence coupled with a loss of medical and social support means that the post-treatment period brings new challenges as well as continuing with existing anxieties. These disrupt women's abilities to return to a pre-illness state, instead necessitating them to formulate a 'new normal' (Mukherjee, 2011b). How they do this will now be explored in the following chapters.

Chapter 3: Research design

In the previous chapter I discussed how the aim of the research is to explore the experiences of women who have been treated for ESBC/DCIS, focussing on gendered aspects of biographical disruption (Bury, 1982) and liminality (Turner, 1969). The current chapter sets out the methodological approach used in this research and how I chose the methods that I felt would be the most effective way of addressing the research questions. I begin this chapter with a story of an event that influenced the direction of the PhD and in many ways sums up the approach I have adopted in the research. I had interviewed my friend Susan after completing my MA, intending to include her in my sample for the current study. At the time she was living with secondary breast cancer and shortly afterwards she found out that the cancer had spread to her brain. She died nine months later. This is my research diary entry:

29th October 2010

Susan died on Monday. Gareth phoned me last night to tell me. He was going through her filofax and ringing all her friends. I know it shouldn't be a shock but it is. I just had kept hoping for a miracle, praying for one. And now it's over. She was only 55. She had only been married for two years. Because I interviewed her I know how afraid she was of dying. I know more than some of her other friends, but that's not good at the moment. Because it's too close to my own fears of dying which

this just brings to the fore. So I'm sad because a friend has died but also I'm selfishly thinking about myself and how much I don't want to die and to leave my family and to die in such a horrible and painful way. And it's all mixed up... It's really hard. I feel tired and confused and sad and horrified that someone so close to me in circumstance and age has died. She's died. Gone. Maybe I can help a little bit of her to carry on by using the words she gave to me before she got too ill. I hope so.

I later wrote that: 'My study has suddenly taken a different feel as there on my computer is a digital recording of Susan's voice talking to me about her fears of increasing disability and of dying. I feel simultaneously privileged and burdened by this legacy from Susan. It has brought home to me the necessity of acknowledging my own emotions in this research.'

This vignette indicates the importance of this topic to me personally, and how I was implicated in it by my insider status. This affected not only epistemological considerations but also ethical and emotional dimensions of conducting the research and analysing the data. Ultimately this renders the study unique but also vulnerable.

I will begin this chapter by discussing the philosophical underpinnings behind my decisions to use a qualitative approach and specifically narrative research. I will then go on to describe the recent rise in popularity of first person accounts of illness. The emotional implications of this type of

research, particularly when it potentially involves interviewing friends or acquaintances, will be discussed with reference to the effect of Susan's death on the process of recruiting participants. I will then describe the way that I proceeded with the research in order to elicit rich data based on our mutual understanding of the breast cancer treatment process, whilst minimising the emotional cost to myself as researcher. Finally I present my reflections on research relationships including a discussion of the benefits and drawbacks of having a shared life experience.

Methodology

In the previous two chapters I have set out the aims of the research. I will now explain why I chose to adopt a qualitative approach using narrative methods from a wealth of possibilities. Qualitative research originates from an interpretivist tradition (Henn et al, 2006), therefore it is suited to this research which aims to understand and interpret women's experiences of ESBC/DCIS. It is based on the principle that the social world cannot be studied adequately using scientific measurements because feelings, emotions and motivation cannot be observed or measured in an objective way (Benton & Craib, 2001). The current study aims for a deeper understanding of the experience of having ESBC/DCIS which often contains many contradictions and inconsistencies which are difficult to capture by quantitative means. Overcash (2003) illustrates this in her description of an incident where women awaiting cancer treatment were asked to complete questionnaires for a psychosocial study. The women wrote unsolicited narratives on the back of the questionnaire papers

in order to better convey their experiences of living with breast cancer to the researchers. In his concept of *verstehen*, Weber suggests that social scientists should aim to study people's understanding through an empathetic identification with an individual social actor (O'Connell Davidson & Layder 1994). The current study aims to understand the phenomena of living with and beyond treatment for ESBC/DCIS and the meanings attached to these experiences through an empathetic relationship between myself as researcher, and my research participants.

Fonow & Cook (1991) acknowledge that a limitation of a small-scale qualitative study is that it is not generalisable. However, the goal of this kind of ideographic approach is to gain a detailed understanding of a particular experience or event. This is based on the assumption that it is better to study a situation in detail than to try to find empirical regularities that supposedly remain constant through time (Fonow & Cook, 1991). This contrasts to the nomothetic approach favoured by quantitative researchers which aims to construct laws which can be generalized (Yates, 2004). However, this does not mean that interpretations are treated as individual things, as meanings are shared within groups, cultures and societies (Dey, 1993). Furthermore, Conrad (1990) argues that concepts relating to chronic illness (such as biographical disruption) can be applied to other samples and other illnesses. Indeed, Bury's (1982) concept was originally applied to a mixed sample of people suffering from rheumatoid arthritis, yet some important aspects of it relate to the current study. Kasper (1994), who interviewed 29 women to find out how breast cancer impacts on a woman's sense of identity, argues that subjective data are valuable by virtue of

their subjectivity. She argues that it leads to a better understanding of how individuals find meaning in an experience and that furthermore, such experiences are often shared by other women. As Riessman (1993:70) puts it: 'we learn about the general from the particular'.

A narrative approach is appropriate for this study. Miller (2005) used this approach in her study of women's transition to motherhood and argues that it is suited to the aim of 'understand[ing] how individuals make sense of, and ascribe meanings to, periods of biographical disruption or transition' (Miller, 2005:19). Meichenbaum (2006) suggests that narratives are stories we tell ourselves and each other about life events such as chronic illness, through which we establish individual and collective meanings. People are natural storytellers and they use stories to make sense of their lives and the world. Narratives are relevant to this study because, as Maynard-Moody & Musheno (2006) point out, stories are a powerful research tool if the root question is not 'how much?' or 'how many?' but rather how do...(people make sense of their experiences?) Graham (1984) highlights several advantages to using narrative methods. Firstly she says that in contrast to traditional interviewing, stories provide a vehicle through which individuals can build up and communicate the complexity of their lives whilst relating events to social contexts. This is important to the current research in view of the need to consider the context in which the participants became ill as highlighted in the previous chapter. Locating the experience of ESBC/DCIS within women's life stories provides a deeper understanding of the extent to which women reported biographical disruption (Bury, 1982; Ritchie & Spencer, 1994).

Graham (1984) further argues that storytelling does not fragment experiences in the way that a question and answer format does, and finally, that narratives safeguard the rights of informants more effectively which can counteract exploitative tendencies of social research. The narrative method is therefore consistent with the feminist aim of allowing women's voices to be heard (Riessman, 1993) which according to Grbich (2007) is important in order to challenge dominant discourses both in the medical world and in wider society. In my research it was important that participants were able to describe their experiences in their own words with an aim of contributing to challenging dominant discourses surrounding breast cancer, as will be highlighted in later chapters.

Patients' perspective

In the previous chapter, I discussed the existing literature surrounding women's experiences of ESBC/DCIS, the majority of which comes from a medical or clinical perspective. However the current research seeks to understand the experience from the perspective of women who have been through it which is an important contribution to the literature (Stacey, 1997; Frank, 1995). As Mathieson & Stam (1995:302) argue, analysis of illness narratives enables us to 'view the culture of illness from the lives of the ill rather than from the perspective of the researcher or the medical system'. Furthermore, Thomas-Maclean (2004) argues that women speaking about their experiences in their own words can contribute greatly to the knowledge about the complexity of life after diagnosis and treatment for breast cancer, which is the focus of the current study.

In health and illness literature, the benefit of insider knowledge is acknowledged by a recent move towards gaining patients' perspectives through illness narratives. Little et al (1998) who interviewed 10 people with bowel cancer argue that narratives provide intimate details of the illness experience which are not captured by medical understanding of illness. This is reflected in a surge in interest in first-person accounts of illness. In the case of breast cancer, personal experiences feature prominently in the literature, for example Lorde (1980), Winnow (1992) and Ehrenreich (2009) have written movingly about their personal and political struggles prompted by having the disease. Other works have been collaborative, for example Butler & Rosenblum (1991) who wrote about the experience of both having the disease and living with a partner with cancer. It is also the case that researchers have brought themselves into research. For example Broom (2001:251) contrasts her experiences of hip surgery and breast surgery and makes 'no apology for the fact that my body and my experience are implicated throughout'. Broom describes her internalization of the stigma of breast cancer surgery and the way that anxieties of her family and friends were reflected in her treatment choices and behaviour. However, Scott (1991) cautions against non-critical acceptance that experience makes an account 'truthful', arguing that experience must be viewed as historically and socially constructed. She therefore emphasises the importance of considering historical processes that position women and produce their experiences. Bury (2001) too points out the importance of recognising the narrative as a particular presentation of events rather than an accurate description. However, Bryman (2004) proposes that narrative analysis shifts the focus from enquiries about *what happened* to how

people *make sense of what happened*. In other words, I was more concerned with the purposes and functions that narratives serve than in seeking 'true' accounts.

Perhaps the main disadvantage of this methodology then, is its heavy reliance on personal judgments. Criticism that storytelling is unscientific is refuted by Overcash (2003:180) who argues that 'narrative is not simply storytelling; it is a process like any other research methodology'. This is reinforced by Murray (2008), who claims that narratives have ontological status because they provide ways of understanding how people make sense of the world. Portelli (1998:37) argues that 'oral sources are credible but with a *different* credibility' (original emphasis). [He further casts doubt on allegedly reliable sources of information such as historical documents which are often written not only after the event but often by people who were not there.] According to Rubin & Rubin (2005) qualitative research accepts that knowledge is subjective and that 'truth' is dependent on an individual's perspective of events. Therefore there may be several versions presented by different people, 'all of which are 'true' in some sense' (Rubin & Rubin,2005:23)

Insider status

'We can never *really* know another's world, we might *just* know our own' (Plummer, 1983:34 original emphasis)

One way of combating accusations of bias is for the researcher to be candid about their reasons for undertaking the research and their personal involvement in it. Feminist epistemology argues that researcher bias affects studies whatever the

methodology because researchers bring their own experience and interests to the project and will select data that they feel meets their needs. In the health and illness literature, Richards (2008:1718) wrote about her experience of kidney failure. She argues that: 'we do not choose our topics accidentally and our motive for researching them is often personal'. Whilst arguing that it is impossible to exclude value judgments from research, feminist epistemologists believe that they are actually desirable since they inspire the pursuit of knowledge (Benton & Craib, 2001). Rather than being disadvantageous, Stanley & Wise (1993) argue that being a member of the social group under scrutiny presents a unique opportunity to represent the views of others. Richards (2008) highlights how generally people with illness or disability are treated as **objects** of study rather than **agents** of study. In the current research my own experience of having had breast cancer informed the research process from the choice of topic, to the selection of feminist methodology, to collection and analysis of data.

In the sociology of health and illness literature, to my knowledge, there are no studies in which the researcher shares (and discloses), a history of breast cancer with the research participants. I anticipate that this study may bring a different kind of knowledge to the topic of breast cancer experience as a result. For example, many participants were forthcoming about intimate details of their experiences possibly because they felt safe to disclose such information in view of our shared knowledge of breast cancer treatments. According to McRobbie (1992), this is consistent with feminist research which aims to contribute a fresh perspective to existing knowledge by utilising our shared experience.

Nevertheless, this level of empathy can also be problematic, as will be discussed in the following section.

Emotions in research

One of the drawbacks of having a shared experience with research participants is that it can be emotionally painful. Cannon (1989) describes the emotional aspects of interviewing 40 women over three years who were living with (and dying of) breast cancer. She wanted to find out how women felt about having breast cancer and how it affected their lives and relationships. Repeat interviews were carried out over a number of months in order for trust to be built up, during which time Cannon formed friendships with some of her participants. Consequently, she was deeply affected by the subsequent death of some of them, particularly those she was closely involved with, which she describes as 'the lowest point of the research project' (1989:75). Despite this upsetting aspect of the research, Cannon maintains that emotional investment was necessary in order to gain deep understanding of the women's experiences.

The importance of acknowledging my own emotions in the research is highlighted by Arber (2006). She argues that keeping a research journal in which feelings and emotions are documented reveals the way that 'the field and relationships shape the researcher and the research' (Arber, 2006:156). My own research journal, which I have cited periodically throughout the thesis, reveals the processes involved in altering the project in order to minimise the emotional impact to myself as researcher. For instance, Susan's death which I described at the beginning of this chapter, happened at the time when I was actively seeking participants. The experience

informed my decision to limit my sample to women who had received curative treatment for early-stage breast cancer (ESBC) or DCIS. I recognised the vast differences in these women's experiences compared to women who knew that they would die as a result of breast cancer. Also, I realised that I did not want to go through the emotional turmoil of interviewing women who were likely to die shortly afterwards, particularly when they were also my friend. Later in this chapter I describe the recruitment process, once the decision had been made to avoid interviewing friends and those with a terminal diagnosis.

Ethical considerations

Ethical clearance was granted by the University of Nottingham to enable me to proceed with the project. All participants were asked to complete a consent form before the interview and I also provided an information sheet which outlined the purpose of the study (see Appendix 1 & 2). Participants were advised that they could withdraw from the study at any time, including retrospectively.

The main consideration ethically, was that the research involved interviewing women about their life experiences at a time when they were potentially feeling vulnerable. It highlights a dilemma of this type of life-history research which is that it can be distressing for people to relive traumatic memories. However, Hollway & Jefferson (2000) dispute whether it is necessarily harmful to become upset especially when participants can talk the experience through with an empathetic listener in a safe environment. Carpenter et al (1999) who interviewed 60 breast cancer survivors felt that

the fact that 90% of the interviewees became tearful during the interview meant that they had successfully established a degree of rapport that enabled the women to explore their deepest emotions. Nevertheless, I followed Silverman's (2006) recommendation and provided contact details of cancer support charities and counselling services on the participant information sheet in case the interview raised issues that participants wished to discuss further.

Due to the sensitive nature of the information, participants were given the opportunity to select a pseudonym. Some women were anxious to preserve their anonymity therefore I used a different name for them as well as removing any identifying features from the transcript at the earliest opportunity. Murphy & Dingwall (2001) maintain this is particularly important where information is placed in the public domain in order for the research to benefit other people. The women who chose a pseudonym tended to choose a name that was special to them (for example their grandmother's name) or one that they had always wanted to be called. Some participants said they did not mind if I used their real names although I decided not to if there was too much identifying data, for example with some of the university employees. Some however insisted that I use their actual name such as Jean who told me she wanted to 'stand up and be counted'. In one case I contacted a participant to suggest that she retrospectively give me a pseudonym because my analysis of her narrative contained potentially identifiable data. In all cases I changed the names of family members referred to in the narrative.

Interviews were conducted in the place where participants selected as most comfortable for them. Of the seven

participants who worked at the University, two asked me to come to their office and the rest chose to be interviewed in the Staff Club which is a restaurant and bar within the university grounds which provides a quiet atmosphere conducive to talking. Four of the other participants opted to meet in public places such as cafes and I interviewed the rest in their own homes. This carried some risk for my safety therefore I followed the guidelines set out in the Social Research Association's Code of Practice for the Safety of Social Researchers' (www.the-sra.org.uk/staying_safe.htm). I always told someone where I was going and asked them to phone me two hours after the start of the interview, unless I had phoned them first.

Sample

Although breast cancer affects men as well as women, this study concentrated on women's experiences because I wanted to explore gendered aspects of biographical disruption and liminality. This encompasses the unique threat to the body, sexuality and relationships posed by treatment for ESBC/DCIS.

The problem with choosing to study women affected by ESBC/DCIS is that they are only identifiable in specific circumstances such as at the hospital or at breast cancer support groups. I decided against recruiting participants through the hospital due to time constraints and also a desire to separate the research from a medical context, as previously mentioned. This left the option used by Komura & Hegarty (2005) who interviewed members of a support group in their study of positive life changes following cancer diagnosis. I therefore began to attend a breast cancer support group as a

participant observer but as a newcomer to a well-established group, I did not feel comfortable in broaching the topic of my request for participants to take part in the research.

I was therefore forced to consider alternative avenues of recruitment which entailed dealing with 'gatekeepers'. Gatekeepers are described by Holloway (2005:292) as 'people who have the power to allow or restrict access to a setting or people'. After deciding to try to recruit participants through a breast cancer charity website, I contacted their research section and sent them an external research application, a project summary in plain English and a copy of the ethical approval. These papers were sent out for peer review which apparently includes a member of their Service User Research Partnership Group or a member of their Research Committee. That was in December 2010 and I am yet to receive a reply.

I also prepared a press release with the help of my supervisors because I wanted a small piece to go in the local newspaper asking for potential participants to contact me. All press releases have to go through the Marketing department at the University. They requested more information about the research project and also some background information about myself to personalise it with my experience. I replied that my supervisors felt that giving too much information about my own experience in the press release would unduly influence the sorts of respondents/responses that I got. Eventually a compromise was reached and the following press release appeared on the University website as 'latest news':

Campus maps Contact us Jobs Help A-Z index **UK Campus** China Campus Malaysia Campus

keyword(s) GO Quicklinks GO


UK Campus The University of Nottingham UNITED KINGDOM · CHINA · MALAYSIA

Home Current students Study with us International Schools and Departments Services for Business Research Alumni About the University

University of Nottingham > News > Press releases > 2011 > January > What is it really like living with breast cancer?

What is it really like living with breast cancer?

Home Press releases 2012 2011 **January** February March April May June July August September October November December 2010 2009 2008 Podcasts Videos



27 Jan 2011 12:27:17.067 PA 26/11

How can we explain the different ways women react to having breast cancer and what effect does it really have on their lives? A new study is being carried out at The University of Nottingham which hopes to find the answers and find new ways of meeting the needs of patients once their treatment is over.

Diane Trusson, a PhD student in the School of Sociology and Social Policy, wants to find women who are prepared to talk about their experience of being treated for early-stage breast cancer (ESBC) and what life has been like since their treatment finished.

Diane said: "Although there is a growing amount of research into breast cancer, much of this work does not address the way that women feel, or their experiences following diagnosis. The main aim is to explore how women who have had breast cancer may have changed behaviourally, physically, mentally and in terms of self perception, as a result of having had a life-threatening disease which may or may not reoccur."

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<http://www.nottingham.ac.uk/news/pressreleases/2011/january/livingwithbreastcancer.aspx> (accessed 8/9/2012)

Almost immediately I was contacted by two women who work at the University. One of them was a woman who I had met at the breast cancer support group but I had not asked her to take part because I did not want to embarrass her. The other one works in the same building as me and it brought home to me that women who have had breast cancer are 'invisible' to each other in everyday life (Lorde, 1989). In the end, seven university employees offered to take part in the research. The implications of this will be discussed later in this chapter.

On the same day as the press release went out, I was contacted by the Marketing department who said that the local radio station wanted to interview me the following morning. The idea filled me with fear and my first instinct was to refuse but I had to remember why I was doing the research and after clearing it with my supervisors, agreed to do it. At 6.40 the next morning I found myself in a deserted BBC building. I had expected to be introduced to the presenter and go through some potential questions but instead I was led into the studio and two minutes later was being introduced live on air. I was terrified but managed to answer all the questions fairly lucidly although listening back to the interview, it seems I was talking through clenched teeth.

By the time I got home I had an email from a listener (Viv) who said she wanted to share her experience 'to help other people'. It occurred to me that going on the radio had presented a means of establishing contact between the two of us that would have been highly unlikely through any other strategy since she did not attend support groups and we had no mutual friends. Also this way of accessing research participants meant that no third party was involved; she could contact me without anybody else knowing about it and my data was likely to be enriched as a result.

The following press release then appeared in two local newspapers:



Nottingham Post 31/1/11

I had several more respondents as a result of this article although unfortunately it did not say that my study was restricted to women who have had ESBC or DCIS². I therefore had to ask respondents if this described them. If so, I said I would be very interested in hearing about their experiences and asked them when and where they would like to meet.

The aim was to interview 20 women but I eventually ended up with 24. Although their ages, length of time since diagnosis and types of treatment(s) differed, the women all had a breast cancer diagnosis in common. Details of the sample are given in the following table and brief pen portraits of each of the participants can be found in Appendix 3.

² Although I had included DCIS with the aim of distinguishing from secondary breast cancer, it turned out to be beneficial in attracting participants who were anxious to discuss their experiences of having DCIS which despite being non-invasive is treated with surgery.

| Name - *Indicates pseudonym | Age | Status(see key) | Children | ESBC/DCIS | Years since diagnosis | Lumpectomy | Mastectomy | Chemotherapy | Radiotherapy | Reconstruction | Interview Location (see key) |
|-----------------------------------|-----|-----------------|----------|-----------|--------------------------|------------|------------|--------------|--------------|----------------|------------------------------------|
| Andrea | 64 | S | N | E | 7/1 | | Y | Y | Y | | C |
| Barbara D | 61 | M | Y | E | 5 | | Y | Y | | | C |
| Barbara PK | 80 | W | Y | E | 20/12 | Y | | | Y | | H |
| Carol * | 50 | M | Y | E | 8 | Y | | Y | Y | | H |
| Catherine | 47 | M | Y | E | 2 | | Y | Y | Y | | H |
| Connie* | 51 | M | Y | E | 7 | | Y | | | | C |
| Gabrielle | 45 | NRP | Y | E | 3 | | Y | Y | Y | Y | H |
| Jean | 72 | M | Y | E | 29/5 | | Y | | Y | Y | H |
| Joy | 63 | M | Y | E | 0.5 | | Y | | | | H |
| June | 73 | M | Y | D | 8 | | Y | | | | H |
| Karen | 43 | M | Y | E | 0.5 | | Y | | | | H |
| Kate* | 47 | RP | Y | E | 6 | | Y | Y | Y | Y | USC |
| Maggie | 56 | M | Y | D | 7 | | Y | | | | USC |
| Malaika | 45 | S | Y | D | 6 | | Y | | | Y | H |
| Martha* | 58 | M | Y | D | 8 | Y | | | | | H |
| Nina* | 53 | NRP | Y | D | 3 | | Y | | | | H |
| Phoebe* | 45 | M | N | E | 6 | | Y | | Y | Y | USC |
| Ruth | 59 | M | Y | E | 4 | | Y | Y | Y | | C |
| Sam | 42 | S | Y | E | 2 | | Y | Y | Y | | H |
| Sandra | 58 | M | Y | E | 9 | Y | | | | | USC |
| Sophie* | 49 | M | N | E | 6 | | Y | | | Y | O |
| Viv* | 44 | M | Y | E | 4 | | Y | | Y | Y | H |
| Wendy S | 57 | M | N | E | 4 | Y | | | Y | | H |
| Wendy Y | 51 | RP | Y | D | 2 | Y | | | Y | Y | O |

Key: Status: M= married, S= single, W= widowed, (N)RP = (non) resident partner; Interview Location: H= home, C= cafe, O= (participant's) office, USC = University Staff Club

The interview process

Flick (2002) recommends starting a narrative interview with a very general question aimed at stimulating the storytelling process therefore I began by asking participants how they first found out they had breast cancer. If they found it themselves, they would describe their journey from person to patient (Zola, 1973). However, this was not always the case, particularly for the women who were over 50 where it was usually picked up at a routine mammogram. However, some participants were less forthcoming than others, and seemed to prefer me to ask them questions. Nevertheless, Holstein & Gubrium (1995) argue that all responses that result from interactions between researcher and participant are narratives, whether they are short answers or life-histories.

Although the participants were encouraged to tell their stories in whatever way they wished, there were some topics that I wanted to cover. O'Connell Davidson & Layder (1994) suggest that even though qualitative interviews are flexible, this does not mean that there is no pre-planning involved. I prepared a series of prompts which could be used to stimulate discussion when participants asked me what else I wanted to know. This ensured that participants were able to include any information that they wanted to talk about yet there were still some commonalities between the women's narratives. These could be used to compare the different experiences reported by the participants. The prompts were informed by Conrad (1990) who argues that the following issues need to be addressed

when focusing on the experience of illness, although not necessarily in this order:

- The impact of the diagnosis/coping with a medical label
- How were relationships affected by illness (family, friends, work colleagues)?
- Adaptations needed to cope with physical discomfort and bodily changes
- Experiences relating to check-ups
- Strategies used to 'get by'

(Adapted from Conrad, 1990:1260)

If these topics did not occur spontaneously then I was able to ensure they were covered during the final stages of the interview. I used open-ended interviews because they provide scope for exploring ambiguities and contradictions which can crop up by using probes such as:

- Clarification (what do you mean by that?)
- Justification (why do you think that was?)
- Extension (can you tell me more about that?)
- Affective (how did it make you feel?)

(Yates,2004:167)

These were important since participants were used to talking about their symptoms and treatments in a medical setting, but were less familiar with being asked about their feelings and emotions.

Murray (2008) argues that a challenge in narrative research is convincing participants that what they are saying is of interest. I used non-verbal signals such as reinforcing mms, nods and smiles to indicate interest and empathy which Silverman (2006) believes encourages the interviewee to talk in depth

and perhaps ascribe their own meanings to their experience. When I revealed my own story, it prompted some participants to engage in conversation about my experiences. At this stage, the interview became more of a two-way process (Oakley, 1981). However, this could potentially be problematic as will be discussed in due course.

Interviews were digitally recorded to ensure an accurate reproduction of events. Recording rather than note-taking meant that I was better able to concentrate on the conversation and be attentive to non-verbal communication (West, 1996). The recorded interviews were transcribed verbatim without aiming to 'clean up' the speech although I did not always write things as they were said in their dialect because as West (1996:334) argues, this can make the narrator seem 'uneducated and backward'. However, unfinished sentences, corrections, slips of the tongue and repeated phrases were included because, as ten Have (1999) argues, such things can all be revealing. I also described emotional responses such as crying or laughter and indicated pauses in the transcript which Wengraf (2001) suggests can indicate where a person is finding it difficult to articulate their answer, perhaps revealing more by what is unsaid. Taking a feminist stance, Kasper (1994) argues that hesitant speech reflects women's difficulty in expressing private views that are contrary to public expectations. Finally, words which were emphasized in the speech were written in **bold** to help the reader to be aware of the way words were said, which can make it easier to understand the meaning. However, as Portelli (2006) points out, there are problems involved in representing oral accounts in written form. For example I had to decide where to insert punctuation in order to present

articulate sentences. Portelli (2006) also argues that it is difficult to convey meaning which is gleaned from the tone and rhythm of speech which can sometimes lead to misunderstandings. This was illustrated when I presented a draft of this chapter to my supervisors which contained the following quote from June:

I feel like you and I could be really good friends, I'm not saying we will be but, we understand one another, you know.

This was perceived by my supervisor as evidence of a potentially exploitative relationship since it suggested that she wanted a friendship with me and did not get one. However, because I was there I believe that from the way she said it, June felt a connection with me that she felt in different circumstances could form the basis of a friendship. This theme of relationships in the research setting is discussed later in this chapter.

Analysis

There was a chance to reflect on the transcripts as I typed them up, which West (1996) maintains is the starting point of the process of analysis. I noted emerging themes and highlighted data that related to these themes. Murray (2008) describes how narrative analysis has two broad phases; descriptive and interpretive. It entails reading the narratives, discerning subplots and considering connections as well as identifying major themes, issues, metaphors and underlying beliefs and values. Miller (2005), who interviewed women about their experiences of motherhood, argues that although narratives are individual accounts, theories can be built on

shared (or different) experiences. The narratives that were elicited through interviews were analysed to find out how women respond to their experience of ESBC/DCIS invoking Bury's (1982) theory of illness as biographical disruption which threatens not only the body but also the mind and everyday life. Nevertheless, the inductive nature of the analysis uncovered a further aspect of the experience, namely the impact of the cessation of formal treatment on women's lives and identities. This became a major focus of the project once I realised the importance of this period to my participants. I read through the transcripts several times and established common themes within them which are presented in chapters 4-7. Because my sample were self-selected, I was able to harness the views of women with a wide-range of post-treatment periods which was beneficial to the quality of data, as will be discussed in later chapters.

Bury (2001) proposes that longer stretches of talk that form the narrative are considered as a whole object of analysis as these reveal the way stories are structured and organized. Sparkes (2005) suggests that:

Asking *how* questions about the narrative initiates reflection on the performative dimensions of storytelling and draws attention to the manner in which they are artfully constructed for particular purposes, at particular times, in specific contexts. (Sparkes, 2005:203 original emphasis)

I have looked at the narratives as a whole to identify where, for example, parts of the story were repeated, perhaps indicating a sticking point which the participant was struggling to assimilate into her life narrative. Additionally, the way that

people describe experiences can be revealing. As Riessman (1993) argues, the object of analysis becomes not what is said but why the story was told in a certain way. For example, when Kasper (1994) interviewed 29 women about their experiences of breast cancer she proposed that each woman recounts examples from her experience that are particularly meaningful for her. This was illustrated by one of Kasper's participant's lengthy dialogue about her hair which had been profoundly damaged as a result of chemotherapy. Consequently, Kasper argues that the participant's hair became symbolic of the overall assault to her femininity by the cancer treatment. Similarly Riessman (1993) found that in her study of divorce seemingly irrelevant information provided valuable context for the analysis. In the current study, Nina described at length how she had been wrongfully arrested seven months prior to her diagnosis. Although at the time she seemed to be veering way off the topic, it turned out to be crucial to the way she interpreted her breast cancer experience and its aftermath.

In the following section I discuss my efforts to have an empathetic relationship with my participants.

Research relationships

'All research involves, as its basis, an interaction, a relationship between researcher and researched'
(Stanley & Wise, 1993:161)

Previously in this chapter I described the background to my decision not to interview friends or acquaintances. I believed that I could still have a sufficiently empathetic relationship with women who I did not know prior to interviewing them, by

virtue of our common illness experiences. This approach is what Cotterill (1992) calls 'a friendly stranger'. This can be beneficial as Cotterill discovered when one of her participants revealed that she felt able to say things in the interview that she could not discuss with medical staff or family members. According to Cotterill, the presence of someone from 'the outside' enabled innermost feelings to be explored. In the current study, this is what happened with Viv who told me:

That's how I cope I think, by just keeping it in. Don't talk about it.

D: mm. Yet you're talking to me about it. Is that because I'm a stranger and-?

V: Yeah. Yeah because you're not gonna be upset by me being upset. But my other friends are, so..

D: so does it ever come up? You know if there's something on the telly or something?

V: yeah, yeah

D: do you talk about it then?

V: Only to my husband a little bit. But not a lot. Try not to. My family are like forgot it's ever happened. Don't talk about it.

D would you like them to talk about it more?

V: yeah

The problems that participants like Viv reported about the difficulties of talking about cancer once their treatment was over, will be covered in chapter 7.

It was important to establish rapport with the participants since I was hoping that they would open up to me about their very personal feelings. O'Connell Davidson & Layder (1994) suggest that the quality of the information gained from the interview depends on the degree of rapport achieved. This is because it is easier to interrupt and keep to the topic if the

participant has warmed to the interviewer. Sometimes I struggled to connect with participants who were employed at the university. Yow (2006) argues that differences in age and social class can affect interactions and I reflected that my position as a mature student from a working-class background perhaps meant that I was intimidated by high-ranking university employees. Also, as those interviews were conducted on university premises (either their office or the Staff Club), this may have made participants more cautious about revealing too much.

It was a different scenario for the women who contacted me after hearing me on the radio or seeing the newspaper article. First I had to show that I was 'normal' despite the fact I was coming from the University which some people seemed a little intimidated by. I felt uncomfortable with this uneven power relationship and tried to find some common ground during a preliminary chat. What we mostly had in common was that we had children or that we had a shared history of growing up in Nottingham, and sometimes there were other points of commonality that I drew upon to put the women at their ease. For example, June wrote to me in response to my press release enclosing a copy of her family tree on which she had indicated all the family members who had been diagnosed with breast cancer. When I telephoned to make arrangements to interview her, June commented on me being 'the young lady from the university'. I responded by telling her that I was the same age as her daughter Trisha. During the interview, June showed me her photo:

D she's the same age as me isn't she?

J course she is. You said that didn't you? When I said about you being a young woman and you said 'I'm the

same age as your Trisha'. And I felt like you was family, you know, 'your Trisha'. I said to Heather, I says, 'it's like she's family'. She said, 'mother,' she says, 'don't talk her to death!' [laughs]

It seems that using the same language was a good way of breaking down the barriers between myself as researcher, and June as participant. In this instance I felt that I was achieving the feminist aim of reducing the social distance between us. The location of the interview also affected the data. Joy told me that she was glad that I had been able to meet her in her own home as she felt better able to express herself:

I'm glad you could come here 'cus you can say more things can't you? And if you get a little bit upset like I was earlier on its a bit embarrassing if you're in a cafe. . in your own home, you're more comfortable. But I quite enjoyed it and if you ever wanted any follow up you've only got to ring me...I mean if I can help you, it's helped me anyway. You don't realise probably how much it has helped me you know to just talk to somebody.

It was clear that being in her home increased Joy's comfort and aided the storytelling process. As Finch (1993:169) also found in her interviews with vicars' wives, the researcher is treated as a 'friendly guest, not an official inquisitor'. In Finch's case, and also in the current research, rapport was enhanced by having had similar experiences although this type of empathetic relationship is not without problems. Yow (2006) for instance reflected that she felt reluctant to ask questions which might cause discomfort to participants who she had warmed to. Rubin & Rubin (2005) argue that although empathy can encourage participants to talk more openly, the emotions and biases of the researcher can affect the types of questions asked and thus, the responses given. A further

consequence was that I had to beware of being problematically uncritical of my participants' responses and/or unquestioningly accepting of their stated rationales for their action. I addressed this through reflection on the interview data, and through discussing possible interpretations with other people including my supervisors who were able to offer a more objective perspective. The findings will be discussed in detail over the following four chapters.

I will now turn to a discussion of further implications of having a shared experience with research participants.

Benefits and drawbacks of shared experiences

Feminist literature has many examples where researcher and researched have shared experiences. The most often cited example is Oakley's (1981) study of motherhood in which she argues that getting people to talk openly is best achieved where there is a non-hierarchical relationship between the researcher and the participant. Ignoring the guidelines on maintaining distance from the 'subject', Oakley answered questions about her own experiences as a mother which she felt promoted rapport and encouraged the participants to think of her as a friend rather than an instrument of data collection. However, McRobbie (1982) believes that Oakley overestimates the similarities between her and the research participants and that simply being female is not sufficient to override differences in age, class, race etc. She also feels that Oakley fails to acknowledge that the women who took part in the study perhaps did so because they felt powerless to refuse. Cotterill (1992) also doubts that such interviews can be the

beginning of lasting friendships as Oakley claims, as often the researcher will not see the participant again once the research is over. Cotterill adds that research participants do not always want to hear about the researcher's experiences as they see the interview as their chance to have their voice heard.

Parr (1998:99) believes there are dangers as well as advantages in conducting unstructured interviews with women who the researcher shares common experiences with as empathy can be a 'double edged sword'. This is outlined by Finch (1984) who drew on her personal experience to interview vicars' wives and found they were very eager to speak to her as it provided them with an opportunity to explore the contradictions in their lives with the help of a sympathetic listener. Finch felt that this placed her in a moral dilemma since she was anxious not to take advantage of the situation by trading on her identity and feared that the women in her study may become vulnerable to exploitation. In the current research when I revealed my own experience to the participants, it altered the dynamics of the relationship. O'Connell Davidson (2008) highlights how this can be difficult to reconcile ethically because participants may reveal more than they would do to someone that they felt no connection with. Therefore, although a different level of intimacy can be beneficial in terms of the data that is collected, it may be construed as an abuse of trust. Reflecting on her friendship with her research participant, O'Connell Davidson (2008) says that it was difficult to decide what could be treated as research data. In some cases she did not use information that might be construed as a betrayal of their friendship.

Another issue is raised by Ribbens (1989) who argues that when female researchers in particular seek to enter another's world through empathetic listening, we may feel the need to nurture those who have talked to us so revealingly. However, McRobbie (1982) feels that it is patronizing to assume participants need our help or that we are in a position to give it. She further argues that in an interview the research is reliant on the co-operation of the participant; therefore interviewers are also in a vulnerable situation. Finally, Cotterill (1992) claims that a research relationship can never be equal because each party has different expectations of the research. In the current research I had the view that talking about their experiences may be beneficial to the participants as well as to me, albeit in different ways. O'Connell Davidson (2008:57) argues that, 'no matter how reflexive, non-hierarchical and ethically sensitive the researcher is, ultimately her..task is to transform research subjects into objects, to fix them in texts..that will be exposed to the gaze of, and consumed by other people'. This ethical dilemma was mitigated somewhat by the fact that some of the women were motivated to participate in the study because they had messages or views that they wanted to air. The interview provided a space for their concerns to be raised which I believe helps to combat the possible exploitative nature of the research. Furthermore many told me that they found it beneficial to do so as the shown by the following extracts from e-mails received after the interviews:

'I found the conversation quite therapeutic!' (Wendy S)

'It was great to meet you! And do talking!' (Andrea)

'I enjoyed 'baring my soul' to you, hee hee'. (Sam)

Not only do these comments suggest that women welcomed the chance to talk about their experiences, but they also highlight the therapeutic value of telling stories, or the 'talking cure' as Freud called it. Brison (2002), who suffered life-threatening injuries when she was raped, tells of the therapeutic value for her, of controlling the narrative which leads eventually to a control of the traumatic memories themselves. However, Roy (2009) cautions that containing such events within a narrative can normalise the experience.

Chapter summary

In this chapter I have outlined the epistemology which informed my selection of the most appropriate methodology and methods to address the research aims set out in the previous chapters. I discussed the relevance of a qualitative methodological framework which, despite its limitations was felt to be the most suitable methodology given that my primary aim was to interpret data rather than measure or quantify it. In particular I outlined the reasons for selecting a narrative approach to seeking to understand women's experiences during and beyond treatment for ESBC/DCIS. I highlighted how it is important not only to let women's voices be heard, but also the voices of people who are, or have been ill (Frank, 1995). This then led to a discussion of emotions in research which emphasised the importance of reflection and acknowledging emotions that affect the research process (Arber, 2006). I illustrated this with the example of the effect on the research design of a friend's death from secondary breast cancer. Finally I reflected on the benefits and

drawbacks of having a shared experience with my participants. On the whole, I have found that my insider status helped to reduce the social differentiation between myself and the participants, and enhanced rapport. This has been beneficial to the type of data that I have been able to elicit, although not without its problems as was discussed. Nevertheless, the intimate details that participants shared with me will help to increase the understanding of the complexities involved in the experience not only of having treatment for ESBC/DCIS, but also the life beyond treatment, which I am referring to as 'the new normal'.

To conclude this section on methodology and as an introduction to the data chapters, I present an extract from an e-mail I received from a participant:

It was good to have my first 'real' encounter with somebody who appreciates much of what I am talking about and that a total stranger can show a true empathy for what I am going through. Likewise, you reflect how I feel I will be in the next few years, hoping to regain **a new normality** in my life, and live it as full as I can, in addition to facing new challenges. I see that the spectre of this period in my life will also continue to be there but it will be about learning how best to not let it affect what I hope will be many years to come (e-mail from Karen 19/5/2011; emphasis added).

The chapters that follow will attempt to do justice both to the experiences of women 'going through' treatment for ESBC/DCIS, and also to the ways in which they 'regain a new normality' when this treatment ends.

Chapter 4. Biographical Disruption and Meaning

Introduction

Previously in this thesis, I have discussed how Bury's (1982) concept of illness as a biographical disruption has been hugely influential in terms of the way that the experience of illness is studied. By looking from the perspective of the patient at the impact that illness can have on people's lives and relationships, Bury argued that chronic illness constitutes a biographical disruption because of the way in which it can fundamentally alter the way that people feel about themselves, the future and their relationships with others.

As a result of his interview study of thirty patients with an emerging illness (rheumatoid arthritis) Bury argued that the experience of a chronic illness is akin to Giddens' (1979) notion of a 'critical situation', in that it disrupts people's beliefs and assumptions about their everyday lives with the stark realisation that death and illness are not just things that only happen to other people. Bury (1982) identified three aspects of disruption; firstly disruption to the taken for granted body, assumptions and behaviours; secondly explanatory frameworks including biography and self-concept and thirdly the resources that people are able to mobilise in order to respond to the disruption.

Bury's (1982) concept of biographical disruption as a result of chronic illness is relevant to the current study because, as was highlighted in the introductory chapter, increasing numbers of

women are surviving breast cancer. According to Cancer Research UK, five-year survival rates reached 85% for women diagnosed with breast cancer in England in 2005-2009, compared with only 52% thirty years earlier (<http://info.cancerresearchuk.org/cancerstats/types/breast/survival/> accessed 13/9/12). As a result, breast cancer has shifted from being understood as an acute illness to a chronic illness; one that alters people's lives in myriad ways and which they must learn to live with by finding ways to cope with and manage their symptoms.

Although the thesis is informed by the conceptual framework of Bury's (1982) seminal work on illness as biographical disruption, I will also be considering suggested extensions of Bury's concept and applying them to the findings of this study. Specifically, the context in which women were diagnosed is considered in view of the arguments proffered by Simon Williams (2000) that sometimes illness represents biographical continuity, and Gareth Williams (1984) who argues that sometimes illness results from biographical disruption rather than the other way round. Although the focus of this research is the post-treatment period, it is necessary to consider the background to the participants' experiences, beginning with the transition from an assumed healthy identity to being diagnosed with early-stage breast cancer (ESBC) or ductal carcinoma in situ (DCIS). Varying degrees of disruption were revealed by the women's narratives through the way that the experience was described, including the use of metaphors which will be discussed later in the chapter.

Central to the experience of ESBC/DCIS are changes to the body which Kelly & Field (1996) argue are highly influential on identity and social relationships. In this chapter I will be

considering the role of hair loss in the construction and repercussions of the 'cancer identity' as this was reported by my participants as most significant in the initial transition from 'healthy' to 'ill'. This discussion of the social consequences of bodily changes will be continued in chapter 6 which will focus on the importance of breasts to the way that women see themselves after treatment and beyond, as well as the consequences for intimate relationships.

Bury (1982) argues that the disruption caused by illness to people's anticipated life trajectory inevitably leads to questions such as 'why me?' or 'why now?' which he describes as finding meaning as significance. In the final part of the chapter I will discuss some of the various explanations suggested by participants for their illness. Janoff-Bulman (1992) argues that exploring people's interpretation of the event and the meaning they attach to it may help us to understand the different ways that people react to a similar event.

The chapter starts with a consideration of the impact of diagnosis as described by my participants.

Diagnosis

The majority of the women in the current study reported that they had been shocked at discovering that they were seriously ill, which seemed to have severely disrupted their view of themselves as healthy. For example, 63 year-old Joy was diagnosed with ESBC six months before I interviewed her and had a mastectomy but no further treatment. During the interview, Joy was keen to stress that she was not used to

being ill and started the narrative by telling me how she had previously been very well:

Bearing in mind let me say to you this; I've never had a day's real illness in my life.

Joy repeated this sentiment several times throughout the interview. It seems that illness was a disruption to the way Joy thought of herself, which she had found quite shocking:

I was shocked because I thought well why me?
Especially that I'd lived a life of nothing, you know, nothing wrong with me at all. I mean I'd only had flu once. The only time it'd made me go to bed was just the once. And you know I'd been so, so fit. And er so I was shocked.

One of the tactics that Joy used to emphasise her previously healthy identity was to contrast her biography with that of her mother who according to Joy, had been ill since childhood. She said:

My mum she was never well. Never. But you see she was 40 when she had me and she was never well. She had heart trouble from when she had rheumatic fever when she was 15. Well in them days you see, she died when I was only 25 and I'm 63 so she's been dead 38 years hasn't she?

Williams (2000) argues that illness for people such as Joy's mother is 'biographical continuity' because it was experienced as an ordinary, even expected, event. Joy seems to have told the story of her mum to emphasise how she had occupied the sick role (Parsons, 1951) for most of her life in contrast to Joy who had not seen herself to be in this role at all prior to

receiving her diagnosis of ESBC at the age of 63. By mentioning her age when her mum died, Joy may have also been ruminating on the similarity between them as, according to her account, her mother would have been 65 when she died.

One reason that Joy may have been so shocked at her diagnosis is that she told me that her cancer was discovered as a result of a routine mammogram rather than finding a lump herself. Consequently she had no time to prepare herself for the diagnosis. Similarly, Boehmke & Dickerson (2006) found that women who had a routine mammogram reported that they were shocked when, instead of getting affirmation of their healthy status, they instead learned that they had cancer. This has interesting parallels with other literature on screening, for example antenatal (Pilnick et al 2004) and smear tests (Forriss et al 2004). Women often view such screening as offering reassurance and therefore it becomes doubly difficult to deal with when it does not. As a consequence of this diagnosis some participants reported that their lives changed 'quickly and chaotically', in much the same way as Jackie Stacey (1997) describes. Recalling her own cancer diagnosis, Stacey comments on how quickly her identity was transformed, saying, 'overnight my identity was reinvented; I was now a cancer patient' (Stacey, 1997:4).

Even where participants reported that they had found a lump through self-examination, they generally told me that they had not been overly concerned at the outset. This is a reasonable assumption as, according to Cancer Research UK, lumps turn out to be benign in 90% of cases

(<http://cancerhelp.cancerresearchuk.org/type/breast-cancer/about/breast-cancer-symptoms> accessed 13/09/12).

One participant, 46 year-old Catherine, told me that she had

previously had cysts in her breasts and therefore assumed that the lump she found would be similarly innocuous. When she was told that it was cancer, she reported her reaction as being:

'I don't understand it, I'm low risk!' Having had little lumps and whatever, I'd read all about it, I thought well I don't smoke, don't drink, I take exercise, I'm light you know all the things, breastfed my children for years, I can't have breast cancer!

It seems that Catherine, in common with many other participants in the current study had thought of herself as healthy and reported being shocked to find out that she was actually ill. She reacted with disbelief and listed the risk factors, none of which she said, applied to her. Part of this shock may be related to the asymptomatic nature of most breast cancers at the time of diagnosis. Several participants reported that they had no other symptoms apart from a lump. For example Phoebe who was diagnosed with ESBC aged 40 said:

If you felt ill it would be a half relief that they had found something and know what it is and all that sort of thing. But because you've felt fit and it's just a lump isn't it? Nothing, no other like physical symptoms really.

Interestingly, only three of the participants had the experience that Phoebe suggested where diagnosis had come as a relief after a period of uncertainty. For the majority however, it seems that the experience of ESBC/DCIS had disrupted the usual trajectory of feeling ill, being diagnosed and then getting better and this disruption can be difficult to comprehend. Extending this theme, 43 year-old Karen said:

I think that's the hard part about this as well is that you're healthy, even when you had the lump you're healthy and it's the treatment that makes you sick.

Karen's comments emphasise one of the differences between ESBC/DCIS and many other illnesses which is that many women feel healthy until their treatment begins. At the time that I interviewed her, Karen was in the midst of a course of chemotherapy and she was alluding to the side-effects she was feeling. She told me that it had become increasingly difficult to prepare herself mentally for the next dose:

If I'm feeling this low now, another lot of chemo (.) it's gonna get harder and harder. It's just that impact really... And people say 'only two left!' I just think 'gosh, I've had four, one's enough!' you know.

Although she acknowledged that the chemotherapy was a necessary part of her treatment, Karen struggled psychologically with returning for another dose which she knew would bring on feelings of nausea and fatigue. The psychological aspects of the treatment for ESBC/DCIS were mentioned by several of the participants as being difficult to deal with. For example, Connie told me, 'breast cancer is 50% there [pointing to her chest] and 50% there [pointing to her head]' and June said, 'that's the biggest thing with women you know. You've got to control this [points to her head], not this [points to her breast]. Do you understand?'

Like the experiences of Bury's (1982) participants who expressed shock at being diagnosed with arthritis, one of the reasons that the diagnosis of ESBC/DCIS was sometimes described by my sample as 'shocking' was discovering that

they had an illness usually associated with older people. For example, Karen told me:

I'd gone there convinced it was a cyst. Because my doctor had said 'oh no' you know, because they look at your age, I was 42 then, and they just see it as 'you'll be alright, it's like a cyst' and whatever but ..[sighs heavily] So you work yourself up to that and to be told **that.**

Karen told me that she had previously worked as a nurse and was aware that cancer mainly affects older people (according to Cancer Research UK, 8 out of 10 women with breast cancers are aged 50 and over). Karen described her sense of disbelief as she sat in the waiting room:

I looked round the rooms and just saw lots of leaflets on cancer, breast cancer and you know and old people get – I know they don't but you know what I mean, old people get cancer so why am I?.. and that's just the, that's the hard part of it.

This was reinforced by Karen's experience of going to a breast cancer support group meeting which, she told me was 'full of older women' who she felt unable to relate to. The suitability of this type of support will be discussed further in chapter 7.

Not only is a diagnosis of breast cancer primarily associated with older women but also some of the participants reported distress at being beset with problems that they perceived to be associated with old age. Bury (1982) highlights that some of his participants felt that they had aged prematurely, although in their case, it was the disease itself that had this effect, whereas for my participants it was due to the

treatment. For example 44 year-old Viv, who reported that she had experienced an early menopause as a result of her treatment, told me:

I've got like, straight into the change so I've got like hot sweats and all that which is awful. And weight gain, a lot of weight gain which I find really hard. Cus I keep fit, I go to at least 10 classes a week..but my weight's creeping up.

Viv seems to be describing a sense of alienation from her body as despite her best efforts she continued to gain weight. The menopause also seemed to have taken some choices away from Viv who told me:

I think it makes you feel old as well doesn't it? cus you can't have no more children. I didn't want them but I didn't want to not be able to!

It seems that the disruption caused by illness has resulted in Viv's life taking an unwelcome trajectory, making her feel old before her time. Even though she told me that she did not want to have any more children she seems to believe that enforced infertility should have come at a later stage in her life and so it was the cancer treatment that had forced this decision on to her instead of it being her choice. In her critique of breast cancer narratives, Couser (1997) suggests that this represents a disorienting change in life phase which some women experience as a traumatic disruption to their life narrative.³

³ One of the limitations of the current research was that the sample did not contain anyone who reported that they were still hoping to have children as this would have represented a major disruption to their future plans.

Trauma narratives

Some of the narratives seemed to display clear indications that the experience could be recognised as a traumatic one. Often this was explicit, for example some participants became emotional when recalling painful memories. For instance, Viv reported that for at least a year she was unable to drive past the hospital without crying, but other signs were more subtle. BenEzer (1999) identified several trauma signals within the life story narratives of 45 young Jewish people who had suffered multiple traumas during a difficult and dangerous journey from Ethiopia to Israel. Despite the different context, I was able to identify some of these indicators in the stories related by the participants about their experiences of ESBC/DCIS. Some of the narratives exhibited sticking points where a part of the story kept recurring perhaps because the tellers had failed to assimilate the experience. BenEzer (1999:35) refers to this as 'repetitive reporting' where an event is recounted, usually in detail, several times during the story. Caruth (1996) also argues that unassimilated traumatic experiences are characterised through behaviour such as unwitting repetition. This was noticeable in the narratives of some of my participants, although not always relating to the cancer experience. Sometimes the ensuing trauma seemed to have neither been acknowledged nor dealt with, as in the case of 75 year-old Jean's narrative which was peppered with references to the first of her two diagnoses of ESBC, even though it had happened 29 years previously. Jean described having a lump removed, but because at 46 she was not considered to be at risk, she reported that she had received no indication that it may be cancerous:

I don't think 100% I realised that you had a lump out, you could be in trouble. I was just having a lump out you know...there was five of us going for this lump and when I went back all of them went in before me..and all came out, they were fine. And I just went in and he told me. Well I was just [pause] speechless.

It seems that Jean was the last patient to be seen that day and had presumed she too would be given the all-clear. Jean described several times how her reaction to her diagnosis was that she was 'struck dumb' as a result of the shock, and returned to this story later in the narrative:

I was dumb. I'd had a lump out and I'd gone back for the results and I re- I don't think, because all those other five had been in and came out fine I think I went in just expecting the same. And it just [pause] I was speechless.

Throughout her story, Jean returned to her reactions using phrases such as 'frightened', 'horrendous', 'nightmare' and 'hell' to describe her feelings but told me how she struggled to put into words how she had felt:

It was **horrendous**. There isn't words in the dictionary to describe what you feel like when you're told.

Jean reported that she had become 'numb' which, according to psychologist Janoff-Bulman (1992:172) is a 'temporary protection against overwhelming distress'. Nonetheless Jean described how she continued to carry out her domestic duties:

It is horrendous. And I felt, I tell you I was just like a zombie walking about, you know getting the dinner ready.

This passage also indicates the gendered nature of the experience as Jean relates the trauma in the context of her everyday life world. It seems that the traumatic nature of her breast cancer diagnosis was apparently not acknowledged, perhaps because it does not fit with the general perception of a traumatic event. As Laura Brown (1995) argues, there is a tendency in scholarly discourse to dismiss traumatic experiences that occur within the everyday lives of ordinary women. She argues that trauma is mainly considered in respect of male-dominated pursuits such as warfare, i.e. what would disrupt the life of a 'white, young, able-bodied, educated, middle-class man' a description that also applies to those who 'write the diagnostic manuals and inform the public discourse, on which we have built our images of "real" trauma' (Brown, 1995:101,102). Despite her obvious shock, Jean reported that breast cancer was never talked about at home, again repeating part of her story:

I just went on automatic, I was like a zombie. I just did everything I did. Nobody ever sp- I told them and nobody ever spoke about it.

In a moving account, Jean told me about visiting her parents' just before she went into hospital for surgery:

I can remember I always went down to me mum's and had me tea on a Saturday afternoon and nothing was ever said about it. And I started my tea and then the tears came. And she just put her arms around me. Nothing was ever said, just put her arms around me.

This was a poignant portrayal of a younger Jean, revealing her vulnerability to her parents, yet being discouraged from speaking about her fears. In fact Jean told me that she had

not done so properly at all prior to talking to me. The issue of being silenced will be discussed in the next chapter but in the context of considering the experience as traumatic it is worth noting the way that the events seem to have played on Jean's mind for so long. She told me:

In a way I have never spoken. The other day I was talking to my friend and I started telling her all that I've been telling you. Now we've been friends for years, I've never sat down...it's all been in here [points to her head]. And you think about it, you do think about it and hopefully doing this, this is what my mate said to me, it might seal it for you, put an end to it. So in a way it is good to talk about it instead of just thinking about it which you know is what you do. And I mean even 30 years on, I still think about all that.

It seems that Jean had not told her story, even to her good friends, until she had agreed to take part in the research. She was expressing a wish to settle the ongoing intrusive thoughts by 'discussing, venting and sharing' them, as psychologists such as Janoff-Bulman (1992:173) recommend that trauma is dealt with. Brison (2002:147), herself a victim of a life-threatening assault and rape, argues that people need 'not only the words with which to tell [their] stories, but also an audience able and willing to hear'. Looking at breast cancer in terms of a trauma offers new insights into the experience. Some of the participants' narratives reveal that they were traumatised at the time and even, as Jean's case reveals, long afterwards which highlights a need to consider ways in which women can be supported more adequately in what can be for some a very difficult time. This will be discussed more in the

following chapter where it is argued that many people enter a liminal state after treatment.

The use of metaphors

Reinforcing the idea that language was inadequate to describe their experiences, many of my participants drew on metaphors in order to convey how they had felt. Gibbs & Franks (2002) examined the metaphors employed by six women in their breast cancer narratives and argue that there seemed to be several themes that women draw upon to try to express their feelings. One of the most common metaphors used in Gibbs & Franks' (2002) research is of cancer as a journey. It was also used in mine by Phoebe:

The emotional journey you're on is far worse than the- I can deal with practical things, I just can't deal with these emotions that went with it.. people don't understand that.

Phoebe's comments suggest that her emotions changed at various points in her cancer treatment and felt that other people were not able to relate to how she was feeling. Another participant, Wendy Y, combined two metaphors as she reported:

I can see at so many..parts of this journey that I could have cracked up potentially...and because of the resources and the coping strategies and whatever else I didn't get to that point. But it would have been so easy because you're so fragile aren't you?

Along with comparing her experience to a journey, Wendy also uses the metaphor of the self as a fragile object which could

have 'cracked up' as a result of what she was going through. Similarly Barbara D's sense of shock at her diagnosis was described figuratively:

I just went to pieces really.. And it took a lot of coming to terms with.. it was a really difficult time. I didn't eat anything for days. Erm just, just shatters you completely. Just everything, everything alters. Your whole life sort of thing.

Barbara is trying to convey the totality of disruption, saying that her 'whole life' had been affected by the breast cancer diagnosis because it 'shatters you' completely. Likewise, Boehmke & Dickerson (2006:1125) argue that in the case of their participants learning that they had breast cancer: 'healthy women had their worlds transformed and oftentimes shattered'. This resonates with Janoff-Bulman (1992:56) who discusses trauma in terms of 'shattered assumptions', arguing that we typically take for granted our indestructibility, but traumatic events can reveal our 'fragility as physical beings'.

When 51 year-old Connie told me that after her diagnosis she was 'in bits', she carried on this metaphor by telling me how she had reconstructed her 'shattered' identity. Connie told me that before she had breast cancer, she had worked as a swimming instructor but after her operation she no longer had the upper body strength she needed to teach lifesaving procedures. Instead she told me that she had immersed herself in fundraising for the ward where she was treated and presented me with several press cuttings detailing the charity work she had been involved with. This was one of many instances where participants told me how their life had changed as a result of having ESBC/DCIS which will be

discussed further in the section on meaning as consequence in chapter 7.

A different metaphor was used by Malaika who described the six week period during which she was diagnosed, had a mastectomy and was told that she needed no further treatment, as a 'rollercoaster'. She said:

It was like being taken up on this rollercoaster very **slowly** and then on the 21st when I got told yep, you know, there's no sign of any aggressive cancer and if you're good to yourself there's no reason you shouldn't live to be 100! And it was kind of like [pause] and then you didn't slowly come down this roller- you know that ride on the fair where you just **drop** and you really do drop. It's like whoa! And then it was over.. everybody started to filter away..apart from your real close friends and family. But that's when my emotional stuff started to kick in. [Participant's emphasis]

The metaphor of a rollercoaster is often employed to describe the highs and lows of a cancer experience but Malaika used it as an effective way of describing the intensity of her emotions. Thinking of breast cancer as a traumatic event helps to explain why participants like Malaika report feeling delayed reactions such as 'that's when my emotional stuff started to kick in'. That this seems to be a delayed reaction is unsurprising according to Caruth (1996) who cites Freud's example of a man escaping apparently unharmed from a train accident yet developing a 'traumatic neurosis' some time afterwards. Caruth argues that it is the latency, the period when effects are not apparent, that leads to unassimilated experiences. For several of the participants, the full

implications of their diagnosis and surgery were not felt until a time had elapsed or, to use Malaika's term, the rollercoaster had stopped. This will be explored more fully in the subsequent chapters which consider the post-treatment period. Malaika already had a twisted spine from an existing health condition and surgery had left her with one breast notably bigger than the other. It seems therefore that her 'emotional stuff' was heavily influenced by this further disruption to her body image. The embodied nature of the breast cancer experience and the social consequences of bodily changes will now be discussed.

Embodiment

For the participants in the current study, embodiment is perhaps one of the most pertinent aspects of Bury's (1982) concept of biographical disruption as a result of illness. This is not only because illness brings into consciousness previously taken for granted body states as Bury proposes, but also the centrality of bodily experiences to identity and the way that people know themselves (self concept). Kelly & Field (1996) emphasise the sociological importance of biological and physical facts because:

- a) 'They impinge directly on self;
- b) They provide the signals for identity production, and
- c) They act as limiting factors on social action for the sufferer.' (Kelly & Field, 1996:251).

This is illustrated by the experiences of one of my participants, Sam, a 43 year-old single mother who had undergone a

mastectomy and chemotherapy. When I asked Sam about the effects of the treatments on her body, she said:

I'm not able to wear a lot of my clothes. I've lost a lot of confidence, my self esteem erm it's very upsetting actually...Because I was so fit and healthy and [pause] vivacious. My friends used to say I was the glamorous one and all that you know. And I feel like I've lost a certain part of that. I really do.

It is noticeable that when asked about her body, Sam talked about clothes, confidence and self esteem. This underlines Kelly & Field's (1996) argument that the connection between bodies and identities means that chronic illness can have a profound impact on the self-concept of the sufferer. In this case it seems that Sam perceives herself as no longer glamorous and there is a suggestion that she is mourning this persona, saying 'I feel I've lost a certain part of that'. Feminist psychotherapist Laura Brown (1995:104) argues that the feeling that 'her old familiar self has gone' is symptomatic of someone who is traumatised.

The role of hair loss in cancer identity

The effects of breast surgery which impacted on the participants' sense of identity and their intimate relationships will be discussed in detail in chapter 6. However, whilst changes to the breast(s) were more dramatic and long-lasting, these were bodily changes that to an extent could be hidden or disguised. A more immediate and highly visible bodily change brought on by treatment for breast cancer was hair loss, which McCann et al (2010) argue is the most visible indicator that someone is undergoing cancer treatment. It is

to this issue that I will now turn because it was cited as a major part of the experience of having ESBC/DCIS, even for women who did not actually lose their hair.

Hair is a central aspect of identity; it forms our impression of somebody, and can be fashioned to indicate lifestyle choices or music preferences. The importance of hair is evident by the multi-million pound hair care industry, with good hair care being equated with self-worth. For example, L'Oreal hair care use the advertising slogan 'because I'm worth it'. Kelly & Field (1996) argue that where illness alters the way that a person looks, it can change the way that they are perceived by other people. In the case of cancer, this is perhaps most obvious where people suffer chemotherapy-induced alopecia. Not all chemotherapy drugs have the same side effects but those used to treat breast cancer tend to result in total alopecia (Hunt & McHale, 2005). This is because they work by destroying all rapidly renewing cells such as those found in hair follicles, stomach lining and mouth. In the current study, eight of the participants reported that they underwent chemotherapy and consequently lost their hair, which in the majority of cases was reported as traumatic. This supports the findings of Munstedt et al (1997) who questioned 29 cancer patients and found that despite the numerous unpleasant side effects of chemotherapy including vomiting, nausea and tiredness, hair loss was felt to be the most traumatic aspect of the treatment by 46% of their respondents. In the current study, 43 year-old Karen was the only participant who was having active treatment when I interviewed her. Karen had been diagnosed six months before I met her, she had undergone a mastectomy and was about to have the fifth of six chemotherapy sessions. Karen was completely bald at the

time of our meeting and told me that the loss of her hair was felt more acutely than the loss of her breast:

I was more affected by that to tell you the truth, I thought I would be fine about it but when it came to the actual, my friend came to shave it off before there was big clumps, I got really really upset.

Hair loss was not only the most visible sign of the transformation to the status of cancer patient but also a more immediate one. What seems to have been particularly upsetting was the speed at which this change happened. 43 year-old Sam recalled the time when her hair started to come out:

We sat in a beer garden, it was the summer and honest to god it was quite, it was a bit windy and my hair was coming out in clumps like tumbleweed

Sam's experience shows that hair loss was something that participants had to come to terms with very soon after starting treatment. Arguably this added another layer of stress to the distress that they were already feeling as a result of their recent diagnosis. Although the majority of the participants who lost their hair reported that they found it distressing, an exception was 47 year-old Kate who told me:

My hair started to drop out. And it was fantastic; because I was convinced it hadn't worked. Because I didn't feel ill, it hadn't worked. And all I could think was, you know it's not worked and then suddenly it just came out one day. And um [laughs] and..I was rea- I was delighted cus it was working and that was the only way I knew it was working. Cus I was taking my temperature

and that was fine, I was doing everything I was supposed to do and I felt just fine.

It seems that in the absence of any side effects from chemotherapy, Kate reported that she was relieved when her hair came out as it represented proof to her that the treatment was working. However it is also possible that she was feeling guilty about not suffering illness as a result of chemotherapy, as most people do. In later chapters I describe how some participants reported feeling guilty because they did not suffer to the same extent as other women; therefore the side effect of losing her hair could have represented relief from guilt. Alternatively, Kate may have been attempting to give a potentially horrific moment a positive twist by seeing her hair loss as a sign of cure rather than a profound disruption.

The importance of hair to identity was evident in the narrative of one participant, 64 year-old Andrea, who told me about her reaction to seeing photos taken when she had no hair:

I don't look like me; they look like another person.

The loss of hair seemed to have affected Andrea's identity to the extent that she reported that she did not recognise herself in photographs. This supports Freedman's (1994) argument that hair loss is not just a biological event, but can be experienced as a loss of self. Underlining the importance of hair in terms of femininity, 46 year-old Catherine told me that she was mistaken for a man when she had no hair:

I remember going out um because I just didn't bother wearing my wig half the time and this little child just couldn't keep their eyes off me you know. It was like my

bald head..and this child said 'Mummy, is that a man or a woman'?

Catherine's reported experience shows how outward appearances that are changed through illness can alter the way that other people construct the identity of the sufferer as Kelly & Field (1996) argue. Hair (or lack of it) provides clues to a gendered identity, and it is unusual for a woman to be seen with a bald head, hence the child's apparent confusion.

Wigs

The visible loss of hair can lead to stigmatization, which is defined by Goffman (1963:9) as 'the situation of the individual who is disqualified from full social acceptance'. Goffman says this happens when people do not conform to the stereotype, in this case, that women have a full head of hair. He also argues that the crucial aspect of stigma is visibility, and this explains why women undergoing treatment for breast cancer are encouraged to disguise their baldness. The cultural impact of a woman revealing a bald head, the chief signifier of cancer, was illustrated in an iconic scene in the popular U.S. TV show *Sex and the City* (<http://www.youtube.com/watch?v=ISET9kt5wfE>). One of the lead characters, Samantha Jones, who in the show is being treated for breast cancer is giving a speech at a breast cancer benefit. She is shown getting increasingly uncomfortable as she suffers with a hot flush brought on by the treatments. Having struggled for some time mopping the sweat away and stumbling over her speech about how the woman with breast cancer could be anyone, she declares, 'oh fuck it, it's me' and takes off her wig to reveal her bald head. There is a moment of silence then one woman in the audience stands up and takes off her wig, followed by many women all

over the room following suit. There is a rousing chorus of approval at this liberating act of numerous women 'coming out' as cancer patients, culminating in a standing ovation for Samantha for initiating it.

Media portrayals such as these are influential on public perceptions of women with cancer, and things like the above scene and the willingness of some well-known women such as Jade Goody to be seen without hair has made baldness slightly more acceptable. Nevertheless, revealing baldness also means revealing the key signifier of cancer which is still stigmatized, as was discussed in chapter 1. Health professionals are aware of the importance of hair to public presentation and social interactions. Roe (2011), who is a consultant cancer nurse, explains how they aim to minimize distress by offering advice and practical help for anyone who wants to disguise their loss of hair. The current practice in the UK is that women who are scheduled to have chemotherapy that is likely to induce alopecia are given a voucher from the National Health Service to redeem at a wig supplier (for example Debenhams) so that they can choose their own wig. Most women tend to opt for a wig that looks like their existing hair, in order to normalise appearance and lessen the shock for other people which Goffman (1963) describes as 'passing'. One of my participants, Gabrielle was 42 when she underwent chemotherapy. She reported that she was not adversely affected by the loss of her hair because she had always had thin hair anyway. However, she went on to tell me about the effect of her hair loss on her young daughters:

I m not sure but the impact on my children was pretty devastating. I think there was a major -I think, you know, watching someone that you love lose their hair.

It seems that Gabrielle used her wig as a way of minimising her daughters' distress. Protecting my children's feelings was also my main motivation for wearing a wig, although the illusion of having hair was sometimes difficult to maintain. For example, the following experience happened shortly after I finished chemotherapy when my hair had not yet grown back:

It was my youngest son's 10th birthday and he had invited several friends back to our house for tea. I was cooking pizza but checking on it meant that I had to take my wig off because the sudden blast of hot air from the oven could melt it. I therefore had to keep the kitchen door closed lest a small boy came in and saw me suddenly bald, crouched in front of the oven. I then had to remember to put my wig back on (properly!) before re-entering the room where the boys were. (13/12/2007)

This vignette illustrates the importance of 'passing' which Goffman (1963) argues is necessary in order to protect 'normals'. In my case I did not want either of my sons to be treated differently because their mum was bald. This assumption is supported by the findings of Frith et al (2007) who interviewed 19 women about their experiences as they anticipated losing their hair through chemotherapy. One of their participants said that she tried on a wig that looked like her own hair which made her feel 'really happy'. This is in line with Bury's (1982) notion that people gather resources in order to minimize the disruption of illness, which in this case was to the women's identities once their hair had fallen out. Frith et al (2007) argue that wigs were perceived to be a form of camouflage and described how their participants would go out in them as a trial run, even before they had lost their hair. The researchers described this as 'behavioural rehearsal' for

the time when a wig would be necessary to disguise their status as cancer patients. Although most of the participants in the current study reported that they used wigs in order to maintain their pre-illness appearance an exception was Kate who was 41 when she was underwent chemotherapy for ESBC. Kate reported that when she learned that she would lose her hair, she had decided to buy a wig that was different to her own hair:

Before it all happened I went out, I bought my wig, the sexiest wig I could possibly find. I wasn't going to look like me, I was going to look like somebody else. I'd got this rock chick hair and everything..brown, dark brown.

It seems that Kate's reaction to illness was to try to create a new persona. When I asked her why she had decided on that strategy she told me:

Oh I decided I was going to have about seven! I was going to have red ones and green ones! I don't know, just do the things that you'd never normally do! It's not forever, it doesn't matter.

It seems that Kate perceived the experience to be a temporary jot in her life trajectory. She reacted to the loss of her hair by embracing the opportunity to alter her appearance in ways that she felt unable to do in 'ordinary life' because her professional role would preclude her from having red or green hair. Alternatively, the choice of wigs that were radically different to her own hair may have been Kate's way of disassociating from what was happening to her and holding the illness at a distance. Her choice of 'red and green' which are not natural hair colours seems to accentuate the difference between the wig and 'normal' hair. Interestingly, she reported

that she chose to look like a 'rock chick' – a stereotypically strong female identity and therefore presumably somebody she felt was stronger than she was and perhaps better able to deal with the trauma of breast cancer treatment.

Cancer identity and stigma

Although wigs are an effective disguise they can also present particular problems because it is important to get it right in order to 'pass' as someone with natural hair. Karen said:

I find the wig very uncomfortable and hot, you can feel it..I've worn it once for a girly night out just after my hair went really and then all the thing about the scarves, I've got loads of hats and scarves and all sorts but it's just the hassle of it, it gets loose, you have to keep redoing it and to me that's- So on the odd occasion I wear a bit of make up just so I don't have that pallor as such but even then I don't do that all the time really I'm too lazy.

This resonates with the experiences of Bury's (1982) respondents who reported that trying to maintain 'normality' constitutes a considerable amount of effort and that the effort falls to the person with stigma rather than other people to accommodate it.

Hunt & McHale (2005) argue that for a woman to be seen without hair can be construed as failure to conform with social norms, therefore there were consequences to appearing in public with no hair, as Karen described:

People look, but then that's human nature isn't it really? And..I stare back at them and they look away quite

quickly so it's just the odd glance you know. But I don't, I think last week it suddenly occurred to me, I don't think about what other people think.

It seems that Karen recognised that her decision to go out in public without covering her head immediately marked her out as abnormal but she would rather put up with the occasional stare than be forced to make the substantial effort needed to 'pass' as 'normal'. However Karen felt that baldness was more natural:

It's very natural for me the way I look at the moment so I'm totally accepting of how I look.. it's a small thing in the whole scheme of things.

Although Karen was right about her baldness being natural (as opposed to an unnatural wig), her lack of hair was contrary to prescribed norms of appearance for a woman. This highlights the difference between normal and natural where society's perception of 'natural' requires considerable work. Karen's bald head provided the necessary cues for her to be identified as having cancer treatment as Kelly & Field (1996) suggest. Although Karen reported that she did not place too much importance on other people's reactions, she recognised that the decision to not cover her head meant that she was revealing information to everybody and not just the people she might choose to tell. Karen reported that she was happy to be bald in front of her family and friends, even posting photographs of herself with and without a wig on Facebook. She was also happy to be amongst strangers, but conversely she told me she was not comfortable to be seen by her neighbours who she did not really know. Goffman (1963) argues that stigma is dependent on previous knowledge about

a person therefore her appearance would be more acceptable to strangers whereas Karen reported that she sensed her neighbours were gossiping about her because they had this prior knowledge.

Another of the participants, 61 year-old Barbara D, reported that she had originally opted to go out without a wig but eventually she came to resent the sympathetic looks that her cancer identity engendered. She told me:

I think the worst thing that bothered me there was people used to look at me and be sort of 'aah'. And then they sort of say 'for the grace of god it's not me'.. it was that sort of, you know. I got to the stage with my hair, I'd had enough sort of that I did get a wig which was great. Again I wanted to move on from people knowing that I was ill to looking different, looking okay again.

For Barbara, the decision to wear a wig was associated with a feeling of leaving the sick role behind, along with the public scrutiny and sympathy that she sensed was provoked by her bald head. However, there are consequences to wearing a wig as Freedman (1994) points out, arguing that disguising baldness prevents people in a similar situation identifying each other and possibly offering support. Catherine told me that she likes to try to connect with other women who have experienced breast cancer:

If I see somebody with extraordinarily short hair, I do ask them..I say, 'is your haircut- ooh your hair's interesting, is it out of choice or not'? And if it is out of choice I say 'it looks really good'! And if they say it's not I say 'do you mind me asking why'? I don't presume its breast cancer, but it usually is.

This shows how women with breast cancer struggle to identify each other and also shows how identifying is a matter of some delicacy. In chapter 7 I discuss how many of my participants valued the support of other women who had been through a similar experience. However, it can be very difficult to identify such women as was illustrated in the excerpt from *Sex and the City*, and also as I found when trying to recruit my sample (see chapter 3).

In some cases, being identified as a cancer patient was reported to have had some benefits. For example most of the participants reported receiving a good deal of social support and Karen, who was working during the time she was having her chemotherapy, told me:

I can get away with murder at work at the moment! It's just, you know, Karen can do no wrong. And I'm milking that I must admit.. but it's, people say to me 'oh this kindness is only time-limited to when you finish chemo!'

Karen seems to be describing the privileges associated with the sick role as described by Parsons (1951) i.e. an exemption from usual obligations and responsibilities. However she reported that she was aware that this was a time-limited concession and feared being expected to resume her pre-illness workload once she began to look 'normal' again:

I suppose it is a concern because as soon as your hair grows back that's it, people, you're all done and dusted, you've had your treatment 6 months ago and it is, I just **know** that isn't it.

Karen is describing the strong association between hair loss and cancer treatment. It seems that there is an assumption

that once hair returns, then people are able to resume their pre-cancer roles and responsibilities and are no longer entitled to the benefits afforded by the sick role. This is to underestimate the traumatic nature of having breast cancer where the immediacy of being thrust into a harrowing course of treatment means that women report that they just deal with the physical aspects of the experience and put the emotional stuff to one side, as previously discussed. Although it had not happened to Karen at the time she spoke to me, she seemed to be aware of the expectations that would arise once she began to 'look normal'. This will be discussed further over the next three chapters which will consider the participants' experiences after hospital-based treatments had finished.

'Looking normal' turned out to be a disadvantage for another participant, Phoebe, who was 40 when she was diagnosed with ESBC. Phoebe is a librarian, and reported that she had an unexpected response when she returned to work after having a mastectomy:

P. They sent an email out, with my consent, to say 'Phoebe won't be shelving, she's waiting for an appointment' you know vague sort of thing, 'won't be doing any shelving, hope you'll all support her in this.' And then I started getting bullied about it.

D. Who was bullying you?

P. A couple of colleagues. They would send me nasty texts and then things on Facebook .. Cus I wasn't shelving. The fact that I would be doing everything else and covering for other people when they were shelving, and they knew everything that I'd had done. I went off

for a couple of weeks cus I was finding it quite difficult. It was 'oh get back to work there's nothing wrong with you'. And then someone else said 'it's all over, what's she-?' You know. And more or less saying I wasn't working, that they were doing all the work. And these were supposed to be sort of friends. They'd known everything I'd had done.

Not only did Phoebe report being unsupported by her colleagues but said that they accused her of malingering. Phoebe seems incredulous at their lack of sympathy despite the fact that she had been very open about her treatment, repeating 'they knew everything that I'd had done'. Phoebe attributed it to having had no visible signs of illness:

I think they thought cus I looked well and I never had chemo. You know if you like lost your hair and you look completely different, I think they might have more sympathy. But because I looked well. In the end I said .. 'what I'm going to do, I'm going to rip my top off and say that's what I've had, that's why I'm not doing shelving!' ..And I think I would have done. It got to the point where I thought 'right I'm just going to have to show them! If they don't believe me, you know, what I've had'. If it's something on your face or.. if you lose your hair they seem like sympathetic but because it's something they can't see, they think it's nothing.

This excerpt highlights not only that this particular illness is unseen, but also breasts are not usually on view therefore it was difficult for Phoebe to 'prove' that she was unable to lift books. As Kelly & Field (1996) argue, appearance is crucial to identity construction and without the physical cues to

support her identity as 'sick', Phoebe's colleagues were apparently not willing to afford her the privileges of the sick role, i.e. relief from usual responsibilities. It seems that loss of hair is so strongly associated with cancer treatment that people who do not comply with the stereotype can be accused of using their illness to avoid responsibilities as Parsons (1951) suggests. Consequently, Phoebe reported that her return to work was the most traumatic aspect of her experience:

In some ways that was worse than all the treatment I've had because you feel like you're going absolutely crazy. The treatment it's sort of practical isn't it? But someone sending you messages and badgering you and.. gossiping about you and you can see them doing it in little corners and you feel like [sighs] and then you daren't tell anybody and I don't know. It was awful.

Whilst Phoebe was able to justify the disruption that the treatment had caused because it was for a purpose, she found the behaviour of her colleagues to be unwarranted and hurtful. This type of negative social support will be further discussed in relation to the intersubjective aspects of cancer treatment in chapter 7.

No hair loss

Phoebe's story illustrates the perceived centrality of hair loss to the accepted cancer identity. She was one of several participants who cited hair loss as a major issue even when they had not gone through it themselves. For example, Connie who had a mastectomy but was advised against having chemotherapy because of other health problems told me:

If I'd had to have chemotherapy that would have been as difficult for me as the surgery. You know, the hair loss and everything else.

This seems to concur with what Connie had previously told me about there being very few people who knew about her cancer diagnosis. This seemed to be more to do with her husband than Connie who told me:

C Jim wouldn't tell a single person. He didn't tell a single person that he worked with, he didn't tell anyone at all, no no.

D why do you think that was?

C he's just like that with everything. Personal things are, you know I think women tend to chat to each other a lot to do with breast cancer and whatever, and men don't. Erm he doesn't at all.

Hair loss would have immediately marked Connie out as having cancer because as Freedman (1994:338) suggests, 'with the loss of hair...the invisible, silent disease becomes visible'. However, as Connie had no obvious signs of the disease, her husband's secrecy could be maintained. Connie seemed to accept this reluctance to share private information with other people as being a male attribute.

Malaika, who was diagnosed with DCIS at the age of 39 and underwent a mastectomy, reported that she felt that she somehow was not perceived as authentic because she did not lose her hair:

I remember a few people said to me when I spoke to them on the phone 'have you still got all your hair?' I

was like yes, what a bizarre question! But that's what they associate with it. And (.) actually, seeing some people give you that, and I became possibly paranoid I don't know but, that thing behind people's eyes where you know 'I had a mastectomy due to breast cancer' and the first thing 'she's got a big head of hair'. You can almost hear the cogs turning with that 'mm? bit strange!' and that's not necessarily what they were thinking but it's just that flicker.

Malaika seems to think that people viewed her as somehow fraudulent because she did not lose her hair and therefore failed to conform to the stereotype of a woman with breast cancer. However she acknowledged that people may not have felt that way and that she was 'possibly paranoid' substantiating Freedman's (1994) suggestion that sometimes women with breast cancer make assumptions about other people's opinions that are actually far removed from what they are really thinking. Malaika reported that she took solace in the fact that even though she had had a breast removed, 'at least' she had kept her hair, perhaps because the breast is hidden whereas hair is so visible. She told me:

I berated myself, I thought 'you're being ungrateful you know there are women out there that aren't surviving this, there are women out there that are losing their **hair** and you're sitting here feeling sorry for yourself.' And so I went through all this mixed emotion, like 'how dare you feel sorry for yourself when you know, you've got off lightly'

Interestingly, Malaika reported that she considered that she had 'got off lightly' which suggests the importance of her hair

to her self-image. This is not to suggest that Malaika is over-concerned with her appearance but the first thing I noticed about her was her mass of long, dark hair, without which she would have looked very different. The importance of her hair was underlined in a conversation that Malaika reported having had with a woman who had been through chemotherapy but not lost the whole of her breast:

[I said] 'you've had aggressive cancer and you've had chemotherapy and you lost your **hair**' and.. she said 'yeah I know but at least I've got my breast'

This extract is interesting in terms of how body parts are weighed against one another in terms of value and significance, in this case hair versus breast. Another factor to be considered is that Malaika also has a twisted spine due to another condition which affects her body image, as mentioned earlier in this chapter. In Goffman's (1963) terms, she already had a 'spoiled identity' because her altered body shape marked her out as different, therefore the loss of her hair as well may have been difficult to deal with. Malaika had indicated this previously when she told me that if she had needed to have chemotherapy, she was 'ready to crumble'. She also reported that she had delayed her reconstructive surgery because she was being treated for her twisted spine and 'couldn't deal with the two situations'. Therefore, although Malaika's comments about her hair may have seemed flippant, they are apparently less so within the context of what else was happening with her body.

Biographical continuity

The importance of context was highlighted by Williams (2000) who argues that the timing and context of illness within biographies may explain the differences in people's experiences of a similar illness. As discussed previously in this chapter, the majority of the participants reported disruption to their lives as a result of illness (Bury, 1982). However, it appeared from their descriptions that the diagnosis of breast cancer was apparently less disruptive for some of the women than it was for others. For instance 64 year-old Andrea reported that she had lost her partner to cancer shortly before she was diagnosed herself and told me that:

I've got a different context with mine. It didn't come to me from nowhere. So that was why I wasn't surprised, because I'd just been through seeing all of that so in a sense nothing would surprise me. Do you see what I mean?

It seems that when her partner died at the age of 40, Andrea had experienced a major disruption to her life and beliefs. Consequently, she reported that the experience had made her almost expect to get cancer herself:

One of the reasons I wasn't surprised I felt like I almost waited for mine. When you see someone so close to you, so young..I thought well why shouldn't it be me? When there's no reason, there was no build up, no, you know, nothing at all..in a way it was completely the reverse of it wouldn't be me; I didn't see why it wouldn't be me.

Andrea acknowledged that she might be expected to question why she had got it but her previous experience had affected

how she dealt with her own diagnosis. This supports Bury's (2001) argument that meaning and context cannot be separated when studying illness. Andrea's comments also indicate how such experiences are not singular and having an insight into the participants' life story as a whole may help to explain why something may be experienced as traumatic for one person but not for someone else. The narrative approach of the current study helps to locate the experience in the context of participants' lives, as discussed in chapter 3.

Williams (2000) argues that the concept of disruption assumes that illness is a shattering event whereas this is not always the case. This was illustrated by another of the participants, 73 year-old June who told me that her mother and sister had both died of breast cancer and so she fully expected to be diagnosed herself. However, June told me that one of her daughters had got breast cancer first and consequently, her own diagnosis came as a relief:

J I think us as a family, we handle it differently. We **expect** to get it, you see. And that's the be-all and end-all.

D so you weren't surprised when you got it?

J No. Do you know what I felt? I thought, cus I felt guilty you know, my girls you know, well Heather had got it and I thought 'well I can look them in the face now, cus I've had it'. Does that sound daft?

Williams (2000:51) argues that in circumstances like these, illness is experienced as 'biographically anticipated'. It is less disruptive than if it was unanticipated, as was reported by the majority of the other participants. As mentioned in chapter 3,

June had sent me her family tree highlighting women who had breast cancer. Kramer (2011) studied the reasons why people are interested in genealogy and argues that for people like June it is 'rendering blood connections visible and making them meaningful' (Kramer, 2011:385). Although a genetic link had not been proven, June reported that she felt that there must be a connection between all the cases of breast cancer in her family and expressed a feeling of guilt that she had passed on this susceptibility to her daughters:

They're saying there's no genetic link but we're surefire proof. I'm positive. Can my mother have it and her sister, then my sister then me, then Trisha and then Heather? That's three clear generations already isn't it?..I must be the carrier, I've got to be the carrier for both Trisha and Heather. I mean Trisha had hers four months to the day after me..she was only 40. She rung up she says..'I've got the same as you.' I said 'what?' you know cus I have asthma and all sorts, she said 'ductal carcinoma'.

June's apparent feelings of guilt at being the carrier of an assumed, although unconfirmed, genetic susceptibility is a common reaction as Hallowell (1999) found in interviews with 40 women at genetic risk of developing breast cancer. Hallowell reported that her participants felt responsible for putting their descendents at risk. She concluded that this ties in with the generally accepted gendered discourse that women, and mothers in particular, feel responsible for other people's health and well-being. A mother's role is to nurture which ironically is symbolised by breasts, therefore June's role of a nurturing mother had been disrupted by her belief that she was a carrier of the susceptibility for breast cancer in her

family. Perhaps in response to this, it seemed to have become June's mission to establish a connection between all the cases of breast cancer in her family. She told me why she had volunteered to take part in the research:

We would like to get in touch with a family like us because we don't know any other family, we only know us. You know, just to discuss what roads they've gone down and that.

From June's description, breast cancer was part of the fabric of her family; she had grown up with its effects and was looking for a chance to share her experience with similar families and perhaps get guidance from them. Furthermore her efforts to prove a genetic link and writing a self-published book containing all this information was aimed at reducing disruption for future generations. As June puts it:

'For our family, being forewarned is definitely being forearmed.'

It seems that adopting this attitude to breast cancer has perhaps harnessed its ability to disrupt the lives of June's present and future family members.

Biographical disruption as chronic illness

Another reason that Williams (2000) argues for consideration of the context of illness within participants' narratives is that in some cases, illness may actually result from biographical disruption (rather than the other way round as Bury proposes). A case in point is that of 53 year-old Nina who started her narrative with the following statement:

The year I got cancer I had so much stuff going on in my life, it was unbelievable. Personally I think that's why I got cancer but nobody ever ever asks you.

It was interesting that Nina thought that someone should have asked her what she attributed the cancer to but nobody 'ever ever' had. Boehmke & Dickerson (2006) argue that from an oncology nurse's point of view, it would be valuable to get a thorough knowledge of a patient's history because nurses need to be aware of the multiple factors that can impact on the way that patients deal with the diagnosis and treatment of breast cancer. According to Kleinman (1988) it used to be common practice for doctors to elicit brief details of a patient's life history including belief systems and coping strategies until these questions were superseded by a more biomedical approach that concentrated on symptoms. Nina's story, which I will return to in the following chapter, illustrates the way that breast cancer arrives in the midst of other life events which can affect the way that the diagnosis is received, and also offers an insight into the way she found an explanation for her illness. Bury (1982:174) argues that people deal with the 'why me? why now?' types of questions by looking at their biography where 'incidents from the past are set against presumed knowledge of the disease's causation'. Nina attributed a series of traumatic incidents that she relayed to me, including being arrested which I will describe later, as the direct cause of her breast cancer:

I just think it's a 21st century illness...I don't know if the arrest was the trauma, I don't know if you do get cancer through trauma or stress..but could it have been something that brought it on really really quick? Cus the shock of that was unbelievable

Although she may have felt that the cancer was stress related, Nina may also have been attaching blame to the arrest because she was so angry about it. Similarly, 43 year-old single parent Sam invoked past life events to explain why she thought she had become ill:

I've had, it's been a very very stressful life. One thing after another. Awful abusive marriage and I left when Beth was 11 months old and started from scratch with nothing. It was only the landlord of this flat ..that I went to see to rent cus I had to do a flit from my marriage, I had a baby with me and he took pity on me... So I got a little part time job and worked my balls off basically to give her a good life and I've always had very stressful jobs where I'm travelling around a lot, targets to meet, this, that, stressed up to the eyeballs you know. Made redundant twice, had no money coming in. Again having to drive all over the country for interviews. It's just been a constant stress, one thing after the other and I'm sure that's what it is .. I'm convinced that that was what it was. Absolutely convinced.

With this lengthy description of her reportedly difficult life, Sam seems to be seeking a meaningful explanation in the context of her own biography in an attempt to restore some sense of order. During her narrative, Sam described her previous experiences of working in extremely stressful jobs in order to support her daughter. Gareth Williams (1984) argues that this can be interpreted as a narrative reconstruction as it reinforced her identity as a single mother doing what she had to do at the expense of her own health. Although Sam seems to believe that her cancer was a result of stress, she is ultimately blaming external circumstances rather than any

failing on her part. In this account, agency is elsewhere and Sam has simply responded to things that were done to her. I will return to both Nina and Sam's stories in the following chapter.

Meaning as significance

The above examples illustrate a common response to a diagnosis of ESBC/DCIS, which was to ask 'why me?' As was seen earlier in this chapter, this is particularly true for the respondents who had previously considered themselves to be healthy and 'low risk'. Bury (1982) argues that illness, especially one where there is uncertainty about causation, often provokes such a reaction and that the search for the cause of illness is conflated with the search for meaning. Lay theories become enmeshed with medical knowledge as people seek to explain why it has happened. For instance my oldest participant, 80 year-old Barbara PK who lived close to the site of a former industrial laundry told me:

I don't drink and I've never smoked so. I mean now this is a funny thing but the laundry had a massive chimney ..and there was always smoke puthering out. Now I don't know whether that could be a factor but at the time there was quite a few of us around here had breast cancer and across the road she died, and 3 doors down she died and this was all about the same time there was quite a lot of us seemed to go down with breast cancer. I don't know what it was and the laundry's not there now. But as I say you don't know what, you can't really prove anything. But I don't think I was in any way to blame for my cancer unless it was the HRT that er triggered it off, I don't know.

Barbara seems to be suggesting a possible environmental cause for the breast cancer that she, along with a number of her neighbours, had apparently suffered during a similar period. Specifically she blamed fumes from a local laundry, although she does not think that could ever be proved. However, some participants suggested that they may have contributed to their illness by their behaviour. For example 61 year-old Barbara D told me:

I didn't breast feed and they gave me tablets to get rid of my milk and I was told at that time, I thought they were just being horrible, saying that taking these tablets could cause breast cancer. I mean that was 40 years, a long time ago, so breast cancer wasn't so in your face then. I didn't know anything about breast cancer. So um whether it came from that you don't know do you?

Barbara seems to have searched her life history for a possible reason for breast cancer and cited this event that had happened 40 years previously. This may be tied up with feeling a moral responsibility at having failed in her role as a mother at least in the eyes of medical staff. Her comment that they were 'being horrible' suggests that she felt that she was being punished because she did not breastfeed her baby. Similarly, failure to breastfeed was amongst a number of causes which 43 year-old Karen felt added to her susceptibility, perhaps because she was able to justify it in terms of possible medical explanations:

Not once have I thought 'why me? why not somebody else?' because I don't see myself as somebody particularly special you know it's 'why not me?' and I tick every, if you look at every um precursor, every

possible risk factor, I'd score **loads** of them..oh absolutely loads of them. Early periods, late children, didn't breastfeed, night working I've even seen they've got tall – height! was a factor you know so ..I think I probably tick quite a lot there really, but that's, that's your genes, that's the way you, you know, and that's your lot isn't it really?

Although not categorically identifying a specific cause for her cancer, Karen seems to accept a certain amount of individual responsibility by listing possible reasons such as having had children late and not breast feeding which very much suggests the gendered nature of this experience. Similarly, the normative role of women as carers was highlighted by another participant, Catherine, who looked at events leading up to her diagnosis that might explain how she had developed breast cancer:

My mum died in April and that was stressful. My dad had died just 2 years prior to that. So I'd cared for both of them. So stress I think might have been a factor. I was just pushing myself when I was tired and carried on pushing myself instead of thinking 'it doesn't matter, I'm going to have a rest now'.

Kearney (2006) who carried out collaborative research with 13 women exploring issues around breast self-examination, argues that such a narrative illustrates how women do not value themselves, and feel unworthy of self-care. This theme was echoed in my research by Gabrielle who said:

I'm not sure that we have an honest view of what causes it and I'm sure there's environmental um I do think stress plays a major part in it and I think

unhappiness plays a part in it as well. I think that there's something about the breasts and there's something about our nurturing. I haven't quite worked it out but there is something that breast cancer is about a lot of elements and um I think there's something about blockages of emotions as well in there..There's a lot of people like Louise Hay, who write about this kind of stuff.. and I'm sure that it is a manifestation of unhappiness as well because I don't think I'd been happy for a long time. But that's me. That's nobody else's blame.

At first, Gabrielle seems to be suggesting that there is some secrecy regarding possible environmental causes of breast cancer. However, she then goes on to describe some of the theories posited in the self-help literature. For example she cites Louise Hay (1984:138) who regards the 'probable cause' of any medical problems with the breasts as putting other people's needs first and not nurturing the self. Hay also suggests that cancer can be caused by 'deep resentment held for a long time until it literally eats away at the body'. This type of literature was selected for particular criticism by poet Audre Lorde (1980) in her cancer journals. Lorde described her reaction to reading a letter in a magazine from a medical doctor that said that unhappiness was a possible cause of cancer:

Despite my knowing better, and despite my having dealt with this blame-the-victim thinking for years, for a moment the letter hit my guilt button. Had I really been guilty of the crime of not being happy? (Lorde, 1980:59)

Mukherjee (2011c), an oncologist, argues that women in particular tend to blame themselves although there is no evidence that a negative mental attitude or stress causes breast cancer. In Gabrielle's case, the idea that breast cancer could be caused by stress, unhappiness and emotional blockages seemed to be the explanation that was most plausible because she could relate it to her (unhappy) life. This kind of self blame is criticised by feminists such as Wilkinson & Kitzinger (1993) who argue that rather than blaming the victim, there should be further investigation into environmental causes of breast cancer. However, it seems that self-blame is a complex phenomenon that cannot be dismissed as easily as some feminist authors suggest. According to psychologists such as Joseph & Linley (2005), people tend to blame themselves in order to retain some control over a traumatic situation as it helps them retain a sense of trust in the world, rather than feeling that they are victim of a random event.

The self-blame narrative was also evident where some of the participants suggested that particular types of people may be more likely to get cancer. For example Sam said:

All the women that I speak to that have had breast cancer are all – I've always been a bit of a people pleaser, all my life you know. Running around trying to make everybody else happy. I think my friend Anne's like that. My friend Jane, she's like that. You know I think that's a similarity, all giving people. And unfortunately a lot of people are just takers and they'll bleed you dry. And then you end up with your battery totally depleted.

In this part of her narrative, Sam is drawing on the metaphor of a body as a container saying that women who get breast cancer have been 'bled dry' and had their 'battery depleted' (Gibbs & Franks, 2002). Sam's comments could be interpreted as a belief in the theory postulated most famously by Eysenck (1994:167) that there is a 'cancer personality.' According to Grossarth-Maticek and Eysenck (1990),

Cancer-prone people . . . tend to be overly cooperative, appeasing, unassertive, overly patient, avoiding conflict, seeking harmony, compliant, defensive, suppress the expression of emotion, and are unable to deal with interpersonal stress, which leads to feelings of hopelessness/helplessness and finally depression . . . This in turn leads to high cortisol levels and so to immune deficiencies." (1990:355, cited in Grossarth-Maticek et al, 2000).

In a study of 'the incidence and mortality of mammary carcinomas' in more than 8,000 healthy women over a 15 year period, Grossarth-Maticek et al (2000) concluded that personality traits such as those listed above combined with physical factors, increased the risk of developing (and dying of) breast cancer, when compared to physical factors alone. However, Sam could also be suggesting that she feels it is unfair that women who are kind and giving should get breast cancer. This came up in another interview where it was not the participant herself that was speculating about the connection between 'being nice' and getting cancer but other people. Wendy Y who works as a nurse told me:

I never thought, cus a few people said 'oh, why you?' sort of thing, you know 'you're a nice person'. And I never thought that. I never thought why me? I thought why not me? Why her? I never went down that road. I never allowed myself.

According to Wendy, it was other people who asked the question about why it should happen to her, and suggested that 'people who said 'why you?' would also say 'why me?' about themselves, although she was not like that. Wendy adds that they said 'you're a nice person' which suggests that they associate a moral aspect to becoming ill. This supports Bury's (1982) argument that in an illness like cancer where the aetiology is rife with uncertainty, the search for meaning encompasses possible moral reasons as well as biological reasons. In Wendy's case, the inference of the reactions she reported is that some people are more deserving of misfortune than others. This theme of injustice will be continued in the following chapter.

However, the desire to attribute a direct cause for their cancer was not a unanimous reaction. Several of the participants seemed to be more pragmatic and reported that they had never gone through this type of questioning. For instance, 72 year-old Jean who had been diagnosed on two separate occasions told me:

What I never ever said was and what you do get people say, why me? Why anybody? I've never ever said that. I haven't and I don't believe you should say that. Its erm why anybody?

Similarly, Wendy chose not to pursue that line of thought:

It's made me realise though that..I've always been a reasonably healthy person but I'm not invincible and.. it can happen to anybody. And you don't think it's ever going to happen to you do you?

Wendy seems to have accepted the arbitrary nature of cancer although she acknowledges the disruption with the phrase 'you don't think it's ever going to happen to you'. This suggests that her previous view of herself as 'reasonably healthy' has been permanently altered.

Religion and spirituality

One reason why some people told me that they had not asked the 'why me?' question was that they believed that some things were beyond their control or understanding. For example Malaika told me:

I never [did] 'poor me,' you know 'why me?' because I felt that everything happens for a very good **reason**, even if we don't know the reason and I have that kind of way of thinking.

This is similar to the story that Gareth Williams (1984) discussed in his study of illness narratives of people suffering from rheumatoid arthritis. He relayed the case study of 'Betty', whose faith in God rendered any search for meaning in the experience redundant. Williams (1984:195) argued that for Betty, 'there was no sense of disruption because her life was part of God's unfolding purpose' and likewise, Malaika appeared to have accepted illness as her lot.

Gabrielle reported that she felt that there was a reason why she had survived treatment for ESBC and was particularly

keen for me to include the story she told me about her spiritual experiences whilst in hospital:

The only thing I was fearful of was had it got into my lymph nodes and it hadn't..and I put that down, I believe that's because of my faith, my spirituality. I **believe** that I was meant to live and talk about my experience. Whether that's a reality but I didn't believe that I was meant to go.

Gabrielle asked me to 'use this experience, please don't let me down' and went on to tell me the story of the night following her reconstructive surgery when she had been told that she had a blood clot which would require further surgery the following morning. She reported that:

During that night there was.. a number of.. I can just say ..they didn't have **wings** you know I sensed a presence; I had a presence of ..I had a **sense** of ..they were almost like spirit figures and they were working down the side of me and then working along the side. And they were communicating and I was being reassured. And it lasted for quite some time and, and then they were gone. And 6 o'clock was there. And these two surgeons came in and they looked at me and they looked at one another and they kept examining me and they said 'it's amazing', they said 'we thought .. it was a formality you know, we listened to you but we came ready to book you in for surgery'. They said 'it hasn't gone entirely but it has moved so **far** from the site that we think you are completely out of danger'. And I said to them 'I felt there would be a miracle, I felt there would be a healing.. And I think you all thought I'd

lost the plot didn't you?' and he said 'oh no..years ago we might have done but peoples belief systems are very powerful and..they're a very important part of peoples recovery'. He said 'well done, you're not going to surgery.'

Gabrielle told me that she wanted me to use it in the thesis as for her it was a crucial part of the narrative and represented the reason for the trauma she had been through. She told me that she found meaning in her experience by her belief that she had survived in order to tell her story (including to me).

Other participants described how they used religion as a resource to help them deal with what they were going through. Nina told me about how she had been comforted by the '*Footprints*' poem [see end of this chapter] and illustrated it with a story about how the poem had cropped up in various forms around the time of her diagnosis. She reported that she had been walking on a beach and did not leave any of her footprints in the sand just as the poem describes and she wondered if she too was being 'carried' even though at that point she had not been diagnosed:

I thought somebody's looking after me, He's saying don't fall yet because you've got some more news to face..that's how I saw it anyway. He was probably holding me under my arms thinking don't go down because you've got to face everything else that's coming up.

Nina told me that this experience, along with being allowed to hold her rosary throughout her operation had helped her to cope and contributed to her sense of peace. Nina said that

although she had previously had faith she recognised that most people would turn to God in her circumstances:

I think that when you're desperate, even if you don't believe, you pray. And I'm sure that even non-believers, if they are on Death Row they must pray

This seemed to be the case with Malaika who appeared to have used religion as part of a psychological coping strategy. She told me about her deal with God:

"If you let me live through this I'll make a deal with you, I will never criticise Christmas again and I promise that I won't waste my life...I'll treasure every minute and be good to my family and ..I'll quit drinking and smoking and I'll never speak a bad word about anybody. I'll live my dreams and I'll never fear anything!" I had this massive list. I thought..if I'm gonna make a deal I want it to be a good deal and thinking, I can't believe I'm actually praying to **God** when I've always been saying 'I don't believe in God really' .. but it was the first thing that I did...Made this prayer and this deal, you know "please, because my daughter can't - she's not ready yet to lose me".

This is described by psychiatrist, Kubler-Ross (1973) as the third of five stages of grief; the first being denial and isolation, the second anger, the third bargaining, fourth depression and finally acceptance. The 'bargaining' phase is described as 'an attempt to postpone [which] has to include a price offered "for good behaviour" [and] sets a self-imposed "deadline" (Kubler-Ross, 1973:72). In Malaika's case the 'price offered' seems to be a complete overhaul of her bad habits and the deadline was when her daughter was able to cope without her:

“If she’s stronger then fair enough. But she’s not strong and she’s got these two young children and she’s going through a rough time and and you can’t bloody do this to me!”

The last part of the ‘prayer’ seems to be an indication of the second stage, anger, but as Kubler-Ross argues, these stages are not necessarily linear. Nina reported that she had done the bargaining twice; the first time was when her children were young and she had a lump removed from her womb:

I used to think, ‘please God I can’t die just yet ,you know, my kids’, I said ‘just give me till they’re older’. Then when you get older and something else happens you go, ‘please wait till I have a grandchild!’

Although Karen had told me that she had no religious faith, she reported a similar process of deal making when she was diagnosed with breast cancer:

I don’t know whether I fully accept, I don’t know whether I, you know, Kubler-Ross and whatever the various stages is, I know I’ve done the bargaining bit because I’ve done the bit before you know ‘just let the boys get to 18 or whatever, independence’ I’ve done that in my head but I don’t know if I’ve gone through the full sort of you know the full acceptance of it. I don’t know, do you ever accept it? I don’t know.

Karen was obviously aware of the Kubler-Ross (1973) model of grief and reported that she had definitely done the third stage of bargaining to be kept alive until her children reached adulthood, but she did not feel she had reached the final stage of acceptance, or indeed ever would do. This ambiguity over

coming to terms with what has happened will be discussed in the next chapter which considers the post-treatment period in terms of liminality.

Chapter summary

In this chapter I have shown how many of the participants in the current study reported that they had their lives and identities disrupted by a diagnosis of ESBC or DCIS, in keeping with Bury's (1982) concept of illness as a biographical disruption. As part of this, I described how narratives revealed the degree of disruption in the way that stories were told and through participants' use of metaphors. These often revealed the traumatic nature of the experience. It was noted that events in the day to day lives of women are not typically recognised as traumatic, even if they bear all the hallmarks. In connection with this, it was argued that a discussion of biographical disruption would be incomplete without a consideration of the role of embodiment (Kelly & Field, 1996) and this is particularly relevant to a study of breast cancer. In this chapter the focus was on the significance of hair loss. In the early stages of cancer treatment, this is the most obvious sign of the 'cancer identity' that the participants discussed, along with its association with stigma (Goffman, 1963). This theme will be taken up again in chapter 6 which discusses the more permanent bodily changes resulting from breast surgery. This includes possible repercussions for women's self-confidence, femininity and sexuality.

In addition to looking at cases where a diagnosis of ESBC/DCIS was experienced as a biographical disruption, I have also highlighted some cases where lives were not

reported to have been disrupted. This was either because participants reported an expectation that they would be diagnosed at some point in their lives which was described as biographic continuity (Williams, 2000), or because the context of the diagnosis meant that this was just one of many disruptive events within their narratives. The consideration of the context in which participants experienced illness is important as will be seen in the following chapter which suggests that biographical disruption can emerge prior to (or subsequent to) diagnosis. Indeed in some cases, previous difficulties in life were described in terms of possible causes for their illness, supporting Williams (1984) argument for biographical disruption as chronic illness. This however was just one of the lay theories expressed by the participants who seemed to seek an explanation for an apparently random event that was meaningful in the context of their lives, in order to re-establish biographical continuity.

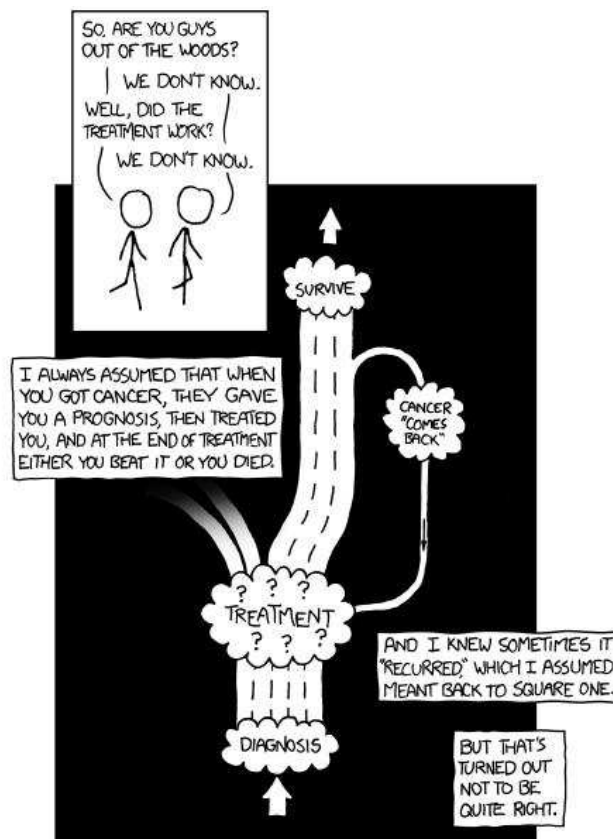
Having discussed the disruption of becoming ill, the focus of the thesis now shifts to the post-treatment period. This starts with a consideration of the ambiguity reported by participants during the transition from the sick role to a 'new normal', which is discussed in terms of liminality (Turner, 1969). Chapters 6 and 7 will then examine what this 'new normal' looks like in terms of bodies and relationships, respectively.

Footprints Poem

*One night a man had a dream. He dreamed
he was walking along the beach with the LORD.
Across the sky flashed scenes from his life.
For each scene he noticed two sets of
footprints in the sand: one belonging
to him, and the other to the LORD.
When the last scene of his life flashed before him,
he looked back at the footprints in the sand.
He noticed that many times along the path of
his life there was only one set of footprints.
He also noticed that it happened at the very
lowest and saddest times in his life.
This really bothered him and he
questioned the LORD about it:
"LORD, you said that once I decided to follow
you, you'd walk with me all the way.
But I have noticed that during the most
troublesome times in my life,
there is only one set of footprints.
I don't understand why when
I needed you most you would leave me."
The LORD replied:
"My son, my precious child,
I love you and I would never leave you.
During your times of trial and suffering,
when you see only one set of footprints,
it was then that I carried you." (Author unknown)*

Chapter 5. Biographical Disruption and Liminality:

A New Normal?



<http://xkcd.com/931/> (accessed 4/8/11)

Introduction

This cartoon by Randall Munroe captures the predicament faced by many cancer sufferers. He reports that he drew it in response to his fiancée's treatment for breast cancer, feeling the urge to draw pictures expressing his feelings about the uncertainty surrounding the experience of cancer

(<http://blog.xkcd.com/2011/06/30/family-illness/> accessed 4/8/11). It illustrates the argument of oncologist Siddhartha Mukherjee (2011b) as introduced in chapter 1, that in cancer treatment there is no longer a binary distinction of survival or death but instead patients may be:

Suspended in limbo...neither cured nor deemed
incurable – neither cancer free nor cancer afflicted.
(Mukherjee, 2011b:27)

Mukherjee argues that after treatment for breast cancer, people enter a 'new normal' state; different from both their pre-illness state and their 'sick' state as a patient undergoing treatment.

In the previous chapters I have discussed how breast cancer has become more treatable. Consequently, increasing numbers of (mostly) women are living in this 'new normality', feeling neither able to describe themselves as healthy or as ill and suffering disruption to their sense of self, relationships and plans for the future (Bury, 1982). In this chapter I will be arguing that the period which Mukherjee describes as 'limbo' can also be described as 'liminality' (Turner 1969) which is applicable to the experiences of the participants in the current study who have finished acute treatment for early stage breast cancer (ESBC) or ductal carcinoma in situ (DCIS).

In the first part of the chapter I will recap the description of the origins of the term liminality as discussed in chapter 2 and go on to discuss how it has been used in previous studies of illness experiences such as cancer. I will describe how the current study has drawn on Bury's (1982) theory of illness as biographical disruption and Turner's (1967, 1969) theory of liminality to further our understanding of the experiences of

women who are living in the aftermath of treatment for ESBC or DCIS. In particular I will argue that facets of liminality can disrupt the way that women perceive their lives and identities. I also suggest that liminality does not necessarily start at diagnosis and neither does it always finish with the end of treatment. Indeed, findings from the data suggest that further biographical disruption may be experienced as a result of the cessation of hospital based treatment which can contribute to this perception of liminality. Examples will be drawn from the data to illustrate how the participants in this study experience liminality both during the sick role and in the transition to a 'new normal' (Mukherjee, 2011b). This theme will be developed further in the following two chapters which will consider what this means to participants in respect of their bodies and relationships respectively.

Liminality

When I was sitting having chemotherapy, I was reading a book on identity for my MA in social science with the Open University. I looked around the ward and saw five other women like me; bald, swollen faced, sitting passively as the noxious life-saving chemicals seeped into our veins. And I thought, we could be anything 'out there'; bus drivers, high court judges, dinner ladies, surgeons. But in that moment, we were levelled. And that is what I connect with liminality. (Personal research diary)

In chapter 2 I described how the term liminality has been adopted from anthropology. Turner (1969) used it to describe the period when tribe members had been removed from their

usual position in society and were undergoing painful and humiliating rituals aimed at stripping them of their power and status in preparation for a new position in society. The in-between state, where people are no longer what they were, but not yet what they will become, is described by Turner (1969) as the liminal state. The above reflection from my own experience of treatment for ESBC highlights the parallels with Turner's (1969:95) observations that this period, when subjects are 'betwixt and between' states, incorporates passivity, invisibility, silence, anonymity and ambiguity.

As was discussed in chapter 2, liminality has been a common theme within health and illness literature since Little et al's (1998) much-cited study of ten patients undergoing treatment for bowel cancer. Briefly, Little et al (1998) argue that cancer is experienced as liminal and commences at diagnosis when patients assume a cancer identity. The consequent loss of control over their time and space is described as 'boundedness'. This is compounded by what they term as 'communicative alienation' as people struggle to articulate their experiences to those around them (Little et al, 1998:1486).

Identifying features such as hair and eyebrows are lost through chemotherapy. Powerless as we sit trapped by wires attached to our veins. No longer able to perform our everyday jobs because we have to be at the beck and call of treatment schedules. Time is not our own. We do not have control over it. Instead there is a kind of frozen time, symbolised by the ice-cold drugs fresh from the fridge, slowly seeping into our veins. Life as we know it has stopped temporarily. What will happen to us

when the needles are removed and there is no need to be here anymore? (Personal research diary)

As the above extract reveals, in my case I felt that liminality started during treatment. However during this chapter I will also argue that liminality is applicable to the experiences of some of my participants either before they are diagnosed with ESBC/DCIS or once they have left the state of being ill with the rights and responsibilities of the sick role (Parsons, 1951). As they are not in a clearly defined state of health, I will suggest that they are in a liminal state of being 'no longer classified and not yet classified' (Turner, 1967:96). Applying this theory in considering the narratives of the participants in the current study who have been treated for ESBC or DCIS can extend Little et al's (1998) theory and offer new insights into the illness experience.

Liminality as a biographical disruption

In the previous chapter, I described how participants experienced diagnosis and initial treatment for ESBC/DCIS. Bury (1991) describes these aspects of people's stories as 'contingent narratives' which are concerned with 'beliefs and knowledge about factors that influence the onset of disorder, its emerging symptoms and its..effects on the body, self and others' (Bury, 1991:268). These narratives revealed varying degrees of the disruption originally proposed in Bury's (1982) landmark study which considered the impact of illness on people's self perceptions, hopes and plans and social relationships. However, Bury's (1982) participants had an emerging condition which revealed the impact of experiencing illness on their lives. They were suffering from a worsening

chronic condition (rheumatoid arthritis) that rendered them permanently in the sick role (Parsons, 1951). To recap, the sick role model proposes that normal roles and responsibilities are suspended until the person gets well. Illness is described as deviant because people are unable to perform their social role and normal life functions (Young, 2004) and people are expected to comply with their doctors in order to get well. In contrast to Bury's (1982) participants, the majority of the participants in the present study have ceased to be easily assimilated into Parson's conceptualisation of the sick role, since the acute stage of treatment is over and they are assumed to be cancer free. However, the experience of cancer is often very different to other health conditions. For example, sociology professor Arthur Frank (2002) compared his heart attack with his experience of testicular cancer and reflects:

'I may have bounced back from a heart attack, but with cancer I was going to have to sink all the way through and discover a life on the other side. Cancer was not going to be an incident; I would have to experience it.'
(Frank, 2002:28)

In the current research, the argument is that even though they have ceased to be in the sick role in the sense that privileges and obligations related to their illness had ceased, women who have had treatment for ESBC/DCIS do not 'bounce back' to the way they were prior to diagnosis but instead enter a liminal state, 'betwixt and between' the worlds of health and illness (Turner, 1969). For these participants, biographical disruption has occurred not only when they initially assumed the sick role but also when they left it and entered this liminal state. Therefore their experiences can be

conceptualized in terms of both biographical disruption and liminality.

The concepts of biographical disruption and liminality have been combined previously in studies of men's experiences of prostate cancer (Navon & Morag, 2004, Cayless et al,2010). These studies extended Little et al's (1998) understanding of liminality to consider relationships and strategies to manage symptoms in the aftermath of treatment⁴. However, these studies were of prostate cancer, whereas the current study uses the concepts of biographical disruption and liminality for the first time to study a cancer that mainly affects a female population. It therefore offers a unique opportunity to consider gendered aspects of biographical disruption and liminality, including the impact of bodily changes and managing relationships during and after treatment. It follows Cayless et al's (2010) recommendation to capture experiences over time. Although Cayless et al interviewed participants three times over the first year following diagnosis, this restricted their data to the period when participants were being medically monitored. In contrast, participants for the current study were between 6 months and 29 years post-diagnosis, consequently their stories have been captured at various stages of their cancer experience. In some cases the passage of time meant that the implications of having been through treatment for cancer were just beginning to surface. This is how 53 year-old Nina described it to me:

It's a bit like [pause] do you know when people go to war, and they come back? All they're bothered about is that they've come back alive, regardless of what's happened and how they've got back alive is irrelevant,

⁴ For a full review, please refer to chapter 2.

it's that you're alive. It's a bit like the cancer and the other incident I had..and this has hit me like 3 years down the line.

In this extract, Nina links her breast cancer experience with another traumatic incident which I will discuss in due course. As in other traumas, (the most obvious being warfare), Nina is describing the how the first instinct is survival and it is not until afterwards that the impact of what has happened has 'hit her'. This is similar to Navon & Morag's (2004) argument that crises often occur once a semblance of normality is restored to people's lives. They reported that this was the point when their participants realised that their life would never be the same again. In the current study, most of the participants had returned to work and resumed their domestic duties but reported that they had changed as a result of their encounter with a potentially fatal disease as well as the ongoing effects of their treatment. This is how Ruth described it to me:

R I think going back to work helped, helped me through it definitely. Get back to normal then, some sort of normality.

D was it normal though?

R well there's a little bit of that, returning to some sort of normality but there's also quite a lot of being left and you know nothing's changed, you've moved on and they haven't you know so it's a strange sort of in-between time I think is the problem.

Ruth described how she had returned to her work as a teacher which represented a welcome step away from the sick role. However, it seems that Ruth felt that her life had altered in

fundamental ways which she was unable to share with other people. Consequently, she reported feeling that it was a 'strange sort of in-between time' which could be described as liminality. By focussing on the post-treatment period, I discovered that for participants such as Ruth, it seemed like everything had changed forever even as everything remained the same. Consequently life beyond cancer as described by Ruth may be what Mukherjee (2011b) means by cancer patients living in a 'new normal'.

Some of the reasons for the participants' perception of liminality will now be discussed, starting with silence and passivity.

Silence and Passivity

Turner's (1969:101) description of the liminal subject sitting 'silently with downcast head, the pattern of all patience and humility' has clear parallels with the passivity associated with the sick role as described by Parsons (1951). In particular, encounters with medical staff and the doctor/patient dynamic meant that some participants felt unable to question the treatment they received. Some of the participants expressed a loss of control and agency upon being diagnosed. For example, Gabrielle reported this feeling as soon as she saw her doctor after discovering a lump in her breast:

I went to see my doctor quite quickly and the minute the doctor confirmed 'yes this is a solid mass, we'll get you seen' and he didn't give anything away at all, he just said 'ah, we'll get you seen'. But from that moment I felt that my cancer stopped being in my control.

Even though she did not know that it was a cancer, Gabrielle describes losing control over 'her' cancer as soon as it was confirmed by the doctor. This may be because having made the decision to seek medical advice, that was the last time she was in control of her body. It seems that the doctor's comment 'we'll get you seen' marked the point that she succumbed to the passive sick role.

Sam is a 43 year-old single mother who described how she felt that she was 'stuck' which seemed to result from her perceived lack of control and agency. Sam described her frustration at not being able to get the reconstructive surgery that she felt she needed in order to move on with her life. It was the theme that she returned to over and over again in her narrative. Sam told me in detail about her current predicament and the conflicting advice she had been given:

[My consultant said] 'Make sure you keep the weight on your stomach, don't lose any weight cus obviously they need it'.. 3 months later, I went to see this surgeon and he said I was too fat for the operation right? He couldn't put me through the operation. I had to go away, lose weight, tone up, come back in 3 months. I didn't really, I wasn't fat. I mean I've lost 7 pounds which is not like life-shattering. So I went back a couple of weeks ago and he said I was too thin now and he didn't know what to do with me. And he still wouldn't put me on the list. So, it's really upsetting because I wanna change I wanna look for other jobs and explore different things and I can't cus there's no way I could start somewhere new and then say to them 'oh by the way I'm going to need 3 months off because I'm having a big operation'

whereas where I am now obviously they understand my situation. So I'm stuck.

Sam's experience as she reports it in the extract above, epitomises liminality because the problems with her treatment appear to make her feel powerless. Sam's frustration seems to stem from not being listened to by doctors which originated with her difficulty getting the original diagnosis:

I had a pain in my chest. It was like a dull ache, it was there all the time and like shooting pains. And I went to the doctors as I say, 4 or 5 times..the last time that I went, [he]said .. 'we don't really think, there's nothing up with you', I said..'There's something wrong. There's something really really wrong.. you know I know my body. There's something really wrong with me'..So two weeks later I woke up with a big lump under my arm and my nipple had caved in. So I went to the doctors and I said you've got to listen to me, I showed him, it was a different doctor, and he said 'right yeah that is serious cause for concern. I'll get you an appointment'.

In Sam's account, she was not taken seriously by doctors until her symptoms had become much worse which Sam believes was too late. Turner (1969:103) argues that silence is a theme of liminality because in tribal societies 'speech is not merely communication but also power and wisdom'. Sam's description of her struggle for a correct diagnosis reveals how she felt doctors would not give her credit for knowing her own body and did not want to listen to her, which made her feel powerless. Not only did Sam report that she was silenced in the medical setting but also within her family who she claims are in 'complete denial':

I can't talk to them about stuff. Because.. as far as my mum's concerned, its dealt with, it's done. Doesn't want to talk about it anymore. Er my dad was just completely in denial, wouldn't accept it. If I tried to talk about it with him he just starts singing [sings] 'always look on the bright side of life!' that's all you get from him. Like he doesn't want to talk about, it's too difficult to talk about so. And [daughter] isn't interested in the slightest. I asked her for something once when I was really poorly and she said 'oh for god's sake, you're so needy! I've got a life'. So that was that. They sound like really bad people, they're not bad people it's just they can't cope with it.

According to Brison (2002:155) who was subjected to a life-threatening assault and rape, it can be horrifying to be unable to talk about a traumatic experience. She argues that 'not to be heard means that the self the survivor has become does not exist' and that recovery depends to a large extent on finding empathetic people who are willing to listen. Thompson (2007) drew on the concept of liminality as used by Little et al (1998), in her study of 9 women with ovarian cancer. She argues that contrary to Little et al's assertion that 'communicative alienation' is due to an inability to find the words to express the experience of illness, the problem is in finding someone who is receptive to listen to it. Sam's experience as she reports it above seems to illustrate Thompson's (2007) argument. Specifically, Thompson argues that this receptive other should be someone who is in a 'similar subjective state', i.e. another woman with ovarian cancer. However, this finding is probably heavily influenced by the fact that Thompson's participants were entirely self-

selected from support groups. Nonetheless, the findings from the current study also suggest that my participants find a great deal of support from other women who have had similar experiences, although in the majority of cases this was not through support groups. This will be discussed further in chapter 7.

One of the best illustrations of the loss of agency as a result of breast cancer is seen in the narrative of nurse manager Wendy Y. She describes a recurrent nightmare of reliving the time she woke from her operation with tubes attached to her that rendered her unable to move:

I didn't feel screwed up or anything by it but there was a niggle. And you know I still dream about the surgery, I still dream about waking up. Being incapacitated. Being vulnerable. And also looking back on how I reacted and could I have done it better? Erm and could any of it, you know, been any different? and did it actually happen? I still can't actually believe that it actually happened. Erm but never sort of sat crying or anything like that, never got massively emotional apart from that tears streaming down my face on that day [of diagnosis] I don't think I ever cried again. I've never massively talked about my feelings but..just little niggles and you know these odd dreams.

Having apparently never talked about her feelings to any great extent, these 'niggles' seem to surface through Wendy's recurring dream. It seems that the feelings of incapacity and vulnerability that she reported having experienced upon waking from her operation have become symbolic of her feelings of powerlessness during the whole experience. Efforts

to regain agency within the medical setting will be discussed later in this chapter.

In the next section, I explore ambiguity which is another aspect of liminality as described by Turner (1969).

Ambiguity

The ambiguity that Turner (1969) asserts is characteristic of the liminal state is evident in a number of the participants' accounts. Looking at narratives as a whole reveals the complexity of the participants' experience: the fear, the anger and the disappointment; but also the humour, the gratitude, the love, the hope, the joy and the desire to help other women going through a similar experience. It was also evident in the non-verbal behaviour of many of the participants who veered between tears and laughter during the course of their illness narrative. This is how 61-year-old Barbara D expressed ambiguity in her narrative:

Yes I am over the moon to be alive but then [pause] I'm also very sad. Yes. Deep down sad. I was told that life would never be the same again and it isn't. It isn't the same.

Barbara is describing her mixed reaction to her experience of having had ESBC, expressing being glad to be alive but also a 'deep down' sadness because of what has happened to her. She seems to be in mourning for the loss of her former life, former body and former sense of optimism. Barbara recognised her many contradictions and mixed emotions in what she was telling me:

It contradicts one another doesn't it? My emotions are all muddled up aren't they really, talking about it?

This seems to be evidence of what Frank (1995) refers to as a 'chaos narrative' which he describes as reflecting the narrator's experience of being on an emotional rollercoaster with their feelings ranging from hope to despair and back again. When I told Barbara about this theory she said: 'that's really true that is, that's really good'.

Sam also described her mixture of feelings since having a mastectomy and chemotherapy:

You can't dress the same, you can't act the same, you can't [pause] have a relationship so it's like living half a life. I mean obviously it's great that I'm still here, and that's the most important thing but that's, and this sounds awful, I'm grateful to still be here because I wouldn't have even wanted to put my **family** through the **pain** of losing me, **BUT** if I'm only living half a life, and I'm gonna be on my own for the rest of my life [pause] what's the point? It's not you know, it's not gonna be a happy life is it? Wandering around on my own all the time, stuck by myself [long pause] What's the point?[pause] That sounds pathetic I know it does. But I've been on my own for years already.
[participant's emphasis]

In this moving account, Sam is describing how she perceives that having ESBC has disrupted her life in almost every way. Although obviously upset, she recognises it seems inappropriate to complain in view of her overriding gratitude to be alive and is finding it difficult to reconcile the mixed feelings. McParland et al (2010) studied perceptions of

injustice in the experiences of people with chronic pain and argue that there is a connection between gratitude and justice. For their participants, to be ungrateful would mean that their pain was justified. People feel compelled to express gratitude in order to continue to get their needs met and, like Sam they do not wish to appear ungrateful. What Sam seems to be most upset about is her loss of a chance to have a 'full life', which based on her comments, seems to be dependent on finding a partner to share her life with. However, Sam believed that her treatment had prevented her from looking for a new partner:

So I'm stuck. I'm single, I can't even think about getting a partner with the way that my body is at the moment because fellas are shallow at the best of times without having to explain to someone that I've only got one boob. So I'm so upset and annoyed at this surgeon, I think it's absolutely appalling the way I've been treated.

According to Turner (1969), one of the themes of liminality is sexual continence and a resumption of sexual relations is a mark of the return to society. In this case Sam seems to be imposing sexual continence on herself because of the way she feels about her body. Sam is expressing feelings of injustice not only because she doesn't feel that she 'deserved' to have been diagnosed with ESBC but also about the way she is being treated by this particular surgeon. She is dependent on him to decide if and when she can have the reconstructive surgery that she feels would enable her to move on with her life. It reveals Sam's perceived lack of agency and the way that responsibility for her predicament has been placed on external factors; the cancer and her medical team. These excerpts clearly reveal Sam's frustration at her perception of being in a state of limbo. She feels unable to move on with her life and

describes various ways in which she is 'stuck' between states. They also reveal the way that Sam feels that agency has been taken away from her as she locates it with the cancer; it is the cancer that she claims is stopping her doing what she wants to do⁵.

The importance of considering the experience of ESBC/DCIS within the context of the participants' biographies is explored in the following section.

Breast cancer in context

Turner (1967, 1969), discusses liminality in terms of a state, however Little et al (1998) argue that the experience of a serious illness such as cancer is better understood as a *process* of liminality. They propose two distinct stages in the process; first an immediate phase of acute liminality which they believe starts at the time of diagnosis, and secondly a sustained liminality which commences when acute treatment ends and continues for the remainder of life. However, examining the narratives of the participants in the current study can call into question Little et al's (1998) proposal that liminality starts at the point of diagnosis. The participants described their experiences of breast cancer in the context of their lives and in some cases this reveals that rather than commencing at the time of diagnosis, as Little et al claim, their current perception of liminality may have been triggered by other life events of which the diagnosis of breast cancer is just one. For example, when I interviewed Nina, she seemed

⁵ In chapter 6 I will be discussing Sam's story further in respect of the impact of her changed appearance on her self-concept and confidence and the effect this had on potential relationships.

to grasp the opportunity to tell me her full story as she relayed the catalogue of events that had occurred prior to her diagnosis of breast cancer:

First of all I'd been bullied for about 6 years...I got arrested, DNA, 4 ½ hours questioning, on the database, photographs, fingerprints..But um ever since then you see nobody's spoken to me about it at work..after that I had to fill in an application form for the team leaders job which I thought I'd filled it in correctly ..and I didn't get shortlisted. So that was literally a week later. Then, in the November my daughter lost a baby at 5 months, that was on a Friday and on the Monday.. I got a letter from the hospital saying come back and see us...I got told I'd got cancer on the Wednesday, on the Saturday I'd sold my house. I'd been struggling with it for two years... And I thought why is everything happening at once? I can't cope you know. Daughter loses a baby on the Friday, Saturday sold my house to the first person that came to see it two years previously, and then er I get told this.

Evidently there had been several major disruptions in Nina's life which illustrates Laura Brown's (1995) argument that what might appear to be a single incident may in fact be the latest of multiple layers of trauma. This was backed up by Nina's comment that:

Obviously the last straw was the cancer and as much as I **was** upset, you know don't get me wrong, but I wasn't as **traumatised** as when I was arrested. I think that just [pause] exploded and took over everything else in my life. [participant's emphasis]

As mentioned in the previous chapter, many of the narratives were characterised by repetition which Caruth (1996) argues is indicative of an unassimilated traumatic experience. In Nina's case, it was the story about when she was apparently wrongfully arrested that she returned to repeatedly during the course of her narrative:

I just assumed they wanted me to be a witness because of what I'd seen, that's what I was thinking, so it never bothered me. But when I got there it was 'right we're arresting you and everything you say will be taken down' and I was thinking 'oh my god!' And then they took me down the cells which was three floors down with all the criminals well with, yeah criminals, and there was like people attached to police officers. And [pause] **that** is the most- that has frightened me ever since. I'm getting over it I think but [starts to cry] they put me in a tiny room you know.. and I think that, that's, it was I mean 4 1/2 hours questioning me.

Although it was not life-threatening like her diagnosis of breast cancer, this event seems to have had a bigger impact on Nina perhaps because she experienced it as a disruption to her perception of herself as law-abiding and trustworthy. It may be that she perceived illness to be a random event whereas she felt the arrest was a personal assault on her identity and she did not want to be seen as a criminal like the people she had been identified with during her detention at the police station. This highlights how generally illness is not stigmatized whereas other forms of social deviance are (Goffman, 1963). In fact Nina cited this and the subsequent traumas described above as the reason why she had developed breast cancer. This was discussed in the previous

chapter which considered meaning as significance. Nina also seemed to blame this catalogue of events for changing her personality and reported that her daughter had said:

'You're not the person you was Mum, why? Why aren't you that person? The one that's so stupid and so like, we're so embarrassed when we go out; because we want you that way. We don't want you being you know, like you are now.'

This seems to be an illustration of Goffman's (1963) argument that it is the responsibility of the individual who has been affected by illness or disability to manage, or 'pass', in order to avoid other people's discomfort. Reflecting on his own experiences of cancer and those of close family members, Frank (2002) argues that ill people expend a great deal of effort in maintaining appearances for the sake of other people. He argues that perfectly reasonable responses of fear and distress in the face of serious illness are discouraged, and instead ill people can feel pressurised to project a positive image in order to make their loved ones more comfortable around them. However, Frank also believes that this comes at a cost. Not only does the ill person lose precious energy, but they miss out on sharing honest experiences with those who care for them. It seems that dishonesty, even when done for good intentions can be detrimental to relationships. This point will be taken up again in chapter 7.

For Nina, her daughter wasn't the only one to notice a difference. She also reported the following conversation she had with a work colleague:

He said to me, 'do you know you'd never know anything different about you but there is one thing missing and'

he says, 'it's you'. And I said 'well I'm still the same person', he says 'no', he says 'where's that daft person that's always laughing and being silly and ..the most immature 53 year old we've ever met? And I said 'oh she's still in here.' He said 'why don't she ever come out?' I said, 'not ready to yet'. He said that and I thought, do you know what I'm going to go and get myself, I want to be, if I can't be 100% like I was, at least let me be 80 or 90% like I was so I can. I wan- [starts crying] I want my granddaughter to remember me as my kids do and not as some miserable old woman.

In this outpouring of emotion, Nina seems to be mourning the loss of her 'old self'. As Brison (2002:156) argues, 'the loss of a trauma survivor's former self is typically described by analogy to the loss of a beloved other', but encouragingly, Nina seemed to believe that her former self is 'still in here' and is trying to find a way to re-emerge. During her narrative, Nina's story veered between past and present. She often tempered the distress with telling me about her new baby granddaughter who seemed to be symbolic of her new hope for the future.

Disruption to future plans

Nina acknowledged that she felt unable to move on although she located this feeling with the arrest that occurred prior to her diagnosis of breast cancer. It seems that both these and other events that she described as happening within a short period of time, disrupted her ability to move forward with her life in the way that she would have if they had not occurred. She told me:

I've had counselling and I understand it now and I know I've changed since 3 weeks ago because I understand that I've been trapped in this 4 ½ hours in the cell [starts to cry] [pause] I think that's the worst thing.

This reveals how Nina can be seen to be 'trapped' in the liminal state which for her is represented by the cell she was forced to spend time in. She used the term 'stuck' when talking about her experience of being wrongfully arrested, saying 'I need to move forward I need to move to today...I'm stuck in that little room'.

I now return to 43 year-old single parent Sam who also used the term 'I'm stuck' repeatedly in her narrative. When I interviewed Sam she was waiting to hear if and when she would have reconstructive surgery following her mastectomy two years ago. Sam reported that she was 'stuck' in respect of finding a relationship, changing jobs and her perceived powerlessness regarding her medical treatment. She described how she had thought that her life would improve when she reached 40 but breast cancer had scuppered that. She told me:

Beth is going to university next year, I'm going to be totally on my own then and I don't want to be on my own. Why should I be? I've had a rotten marriage and a rotten time and I'd just got to the stage, it was my 40th birthday I'd had a great time with all my friends and family and I remember sitting there and thinking 'oh, life really does begin at 40. Beth's a little bit older now and getting a bit more independent, so I can start thinking about myself now,' you know. Its hard work bringing up a child on your own but I did it and I thought, 'it's my

time now' and then 11 months later I was diagnosed with cancer!

Sam described her life as being on hold since she had become a single parent when her daughter was a baby. She claimed that since then, all her time and efforts had been dedicated to looking after her daughter. Sam's story also illustrates the sense of unfairness often associated with illness diagnosis which was discussed in terms meaning as significance i.e. why it happened, in the previous chapter. The theme of injustice was threaded throughout Sam's narrative. In their study of discourses of justice and fairness in patients with chronic pain, McParland et al (2010) cite the 'Just World Theory' which proposes that the general view held by most societies is that people get what they deserve. It seems that people who think that what happened to them is unfair can find it harder to adjust, as Sam seems to illustrate, whereas people who describe their illness as 'just one of those things' are more accepting of the situation. Sam's comments suggest that she felt she deserved a chance to try to improve her life after devoting so much of it to bringing up her daughter single-handedly, yet the experience of having breast cancer had taken away her sense of optimism about the future. This is consistent with Bury's (1982) argument that biographical disruption as a result of illness includes rethinking future plans and expectations as life takes on a different trajectory as a result of being ill. It seems that Sam had decided that it would be possible to make some changes to her identity when she became 40 but instead she was prevented from moving on in the way she had hoped, hence her repeated use of the word 'stuck':

My life's changed a lot really, erm I've always been a do-er and [pause] now I'm just stuck.

This quote illustrates Little et al's (1998) argument that liminality is characterised by 'boundedness' because Sam is explaining how her situation is constraining her. Both Sam and Nina expressed an inability to move on with their lives, and appeared to be living in a constant present. This is discussed in the following section.

Alteration of perception of time

The experience of having ESBC/DCIS was reported to have come as a shock for most of my participants, as was discussed in the previous chapter. One of the consequences of this was an alteration to their perception of time. Some women talked about feeling that they would die young and had a sense of foreshortened time. For example Sam told me about a dream she had where she was celebrating her 46th birthday in a cancer ward which she sensed would be her last:

I had a dream and it was about [blows] 10, 15 years ago? And I dreamt that I was in a cancer ward, in a wheelchair, bald head and all my friends and my family were there and my mum got this big cake out with 46 candles. And it was my last birthday cake. I was only going to live 'til I was 46 and that was my dream. So you can imagine, when I got cancer, the dream. And I thought 'shit!' er I don't think I'll live very long.

Sam told me that this had influenced her to such an extent that for example apparently she had only taxed her car for 6 months rather than a year. It seems that for Sam, life is

temporally contained and confined to the present. Another participant, Barbara D, explained how this feeling of time running out had caused her to be irritated by people and situations who she perceived to be wasting her time.

I'm cross. I'm very cross. I'm very impatient. Extremely impatient. I was always impatient but I'm doubly now. Everything's got to be done now. Er I'm quite difficult to live with.

D why's that?

B because I see the urgency of things I suppose. I don't know, I don't know how long I'm here for so. And there's people say to me 'well nobody knows that', you know, 'you could get run over by a bus' but it's a different sort of. I live every day with erm I worry about it coming back.

Barbara is talking about the way that her perception of time has altered as a result of actually being in a life-threatening situation which she described as 'different' to the vague, and oft-cited, threat of 'you could get run over by a bus' type of comment. Her reported need for everything 'to be done now' reveals a particular focus on the present, perhaps because there is a perceived lack of a future. This was picked up by Rasmussen & Elverdam (2007) who studied the perception of time for cancer patients. They argue that:

Time is an essential aspect to the flow of life, a flow that is disrupted by the diagnosis of cancer. It is a disruption that involves reorienting life and the understanding of time (Rasmussen & Elverdam 2007:615).

It seems that time is one of the facets of life that was previously taken for granted yet assumes a new significance when people become ill. Rasmussen & Elverdam argue that their participants' confrontation with death meant that they were more selective about the way they spent their time and with whom. In the current study, Sam told me that some of her friends had not been supportive during her treatment and she was considering cutting ties with them:

Sometimes I really feel, I have to fight the urge to say to people 'do you know, I really can't be bothered with you anymore, you're such a selfish pig! Just clear off!' you know, I really want to say that to people sometimes er but instead you just try to phase them out of your life don't you?

The issue of social support will be investigated further in chapter 7 where I will discuss how participants reported that some relationships were altered for better or for worse as a result of illness.

For some participants, their experience of ESBC/DCIS seemed to have given them a different perspective on how they should use their time. For example, 59 year-old Ruth told me:

I'm quite sure I won't live very long, I'm quite convinced I won't live very long and I wish they understood that [laughs] I mean I might live a long time but I don't expect to. So I'm going for every moment of my life being a good one

Ruth seemed to be frustrated about the lack of understanding from other people that she no longer took a long life for

granted and therefore was seizing opportunities in the present rather than putting things off:

I decided to go and see all those places I want to see, I've been whittling down the list of what I want to do and see so I've done several of those, there's are still one or two places which I'm working on. But I'm working on the principle that I'm not going to be around for long so [laughs] might as well get on with life

D and then if you are around-

R yes that's right, I won't have lost anything. Apart from some money. I think it makes you realise that if you want to do anything you've got to get on and do it.

Having been robbed of her assumption of having a long life, Ruth appears to be reclaiming what future she has, by pursuing her wish list of places to visit, rather than putting it off. Ruth's reported change of philosophy was echoed by many of the participants who had altered their lives in various ways. These will be discussed in chapter 7 in consideration of Bury's (1982) theory of meaning as consequence.

Fear of recurrence

One of the reasons why participants seemed to have a feeling of foreshortened time was because they were aware that although their ESBC/DCIS had been apparently successfully treated, there was a possibility that the cancer could return, either in the breast or elsewhere in their body (Cancer Research UK, 2012). The fear of this seemed to be a major factor in the experience of liminality since some participants reported that they were not confident that they were now in a

state of good health. Some of the women told me how they interpreted any ache or pain as a possible sign of recurrence such as 44 year-old Viv who had a mastectomy who said:

I always think about it coming back, I think about that all the time. When I get, if I get backache, I had backache about 6 months ago. I went to the doctors and he gave me an x-ray just in case it spread. But it hadn't. But that's the first thing you think. A slight ache 'ooh it's come back!' but I suppose that's what it's gonna be like for the rest of your life. Not a lot you can do about that.

Some participants, such as Viv, seemed particularly worried that cancer would come back in another part of their body. Studying the participants' life narratives offers the opportunity to see where some of the women's fears may have come from. For example Viv told me that she had been caring for her mother-in-law at the time that she was diagnosed with breast cancer. When her mother-in-law died two months into Viv's treatment, Viv had to arrange the funeral:

She got secondary bone cancer during my treatment. It was like I was going to visit her in hospital and then had to arrange her funeral, god that was awful. Cus you're thinking 'ooh it could be me'

It seems that being so close to somebody dying from a disease with the same name as hers was traumatic for Viv. Her comment that 'it could be me' suggests that she was confronted with her own mortality. This shows that the particular disruption of breast cancer and its liminal afterlife is continuous with other life experiences and therefore has to be understood in relation to personal biographies as a whole. It also raises interesting issues about trauma which cannot be

studied only in terms of the episodic and disruptive but through the course of a life, including the seemingly 'normal and everyday'. Viv's experience is an example of the way that narratives can shed light on the various ways that different women react to a similar event in their lives.

Rather than having an assumption of health, participants' accounts such as Viv's above also seem to suggest an ambiguous state. This is consistent with Arnold's (1999) argument that the main fear of people who have been treated for cancer is that it will reoccur; this was the fear expressed by all but one of the participants in her study. It seems that having had cancer means people no longer have a sense of security in their body; it has let them down before and it may do so again and they react by hyper vigilance. For instance, in Viv's case, she assumed that backache was a sign of recurrence. This type of heightened vigilance is highlighted by Brison (2002) as indicative of someone who has been traumatised. Brison argues that it is a physiological response to having had a life-threatening event. In the case of breast cancer it is unsurprising that women are hyper vigilant because there is a considerable amount of emphasis on self-monitoring by means of self-examination in order to detect and treat any cancer at an early stage. Moore (2008) argues that being 'breast aware' can manifest itself as constant body-monitoring which can induce anxiety even for women who have not experienced breast cancer.

Even when participants seemed to have no reason to feel uneasy about their health it seemed that the perceived threat of recurrence could impact on their plans for the future. One participant, 63 year old Joy, told me that her husband's stroke had affected their ability to make plans but actually she

seemed to be putting plans on hold in case her check up revealed a need for further treatment. This is despite the following conversation she reported with her consultant:

He says 'right well I've got good news for you, you are all clear'. I says 'all clear?' just like that and he says 'yes, it's all gone. There isn't anything there whatsoever'. And then I cried [starts crying] because I was so [crying] and I wiped my tears and I said 'thank goodness for that'. He said 'yes you can do just what you like now.'

This was the only time in the interview that Joy cried as she recalled the relief she felt at being told that she no longer had breast cancer. However, it appears that despite her consultant's seemingly categorical statement that her cancer had 'all gone'; Joy remained anxious about her forthcoming check-up:

I do just worry a little bit about August you know because I thought 'oh god, it'll be my luck', you know. I thought I might change it to September because we'd like to do something for Ben's birthday but I thought 'ooh you might regret it if you postpone it' you know.

Joy's worry over the possibility of her cancer recurring seems to have taken precedence over the desire to celebrate her husband's 65th birthday. It seems that Joy did not want to postpone her check-up in order to celebrate it in case the mammogram revealed a recurrence of cancer and there would then be a delay in treatment. When I asked Joy whether she worried about it coming back, which is what she had been intimating, she said:

I mean it could well come back. I mean you listen to the radio and I mean I'd never heard it before but they was talking about illnesses and that and he said if you've had breast cancer once you'll probably die of breast cancer.

It appears that Joy may never view herself as healthy again. Even though she had not been given any specific medical or physiological reason to suspect that the cancer may come back, Joy seemed to have lost faith in her body to remain healthy. This shifts our understanding of healthy as free from disease to this liminal state where the boundaries of illness are blurred (Blaxter, 2010) which for many of the women constitutes their 'new normal'. Breaden (1997) who interviewed six women who had been treated for various types of cancer, argues that when people are diagnosed with cancer, 'plans for the future are temporarily arrested...how can a future be planned when there may be no future?' However, Breaden notes that this is not permanent and in the current study this is shown in the comments of Barbara D who was 5 years post diagnosis when I spoke to her:

At one time I couldn't go to book a holiday or book something months in advance or what have you, cus that frightened me. I couldn't look forward to something I might not be able to enjoy. That's gone, that's gone now. I just think 'oh sod it! If I can't go I can't go.'
[laughs]

Although she reported that she still suffers from fear that the cancer will come back (as was discussed in the previous section), it seems that it no longer prevents Barbara from making plans. This may be because Barbara was further from diagnosis than Joy who had been diagnosed just six months

before I interviewed her. Barbara's apparent contradiction is also further evidence of her 'chaos narrative' (Frank, 1995), as mentioned at the beginning of the chapter.

Joy's fears of recurrence seem to have been reinforced by what she told me she had heard on the radio. Similarly, Barbara said:

It's in the papers all the time, somebody that's got it or recovering from it or erm and I find that quite difficult to cope with. And its good, because it makes people aware of it but it isn't always good for everybody..it's just reading about things you know, 'thought she'd got over it' you know 'its 5 years then a month later she drops dead' you know it's those sort of things that really bug me. They really sort of eat into you somehow.

Barbara's mention of 5 years is significant because this is the point at which survival time is measured and so participants seemed to associate this with a point when they could relax somewhat about recurrence. Barbara who was herself 5 years post-diagnosis, therefore probably did not want to hear on the news that someone had reached 5 years and then 'a month later she drops dead' as it resurrected her fears. In the current study, many of the participants talked about the representation of breast cancer in the media. They commented on how it is often featured in newspapers, magazines and on television in both fact-based programmes and fictional dramas. In the UK and USA, October is the designated breast cancer awareness month and there seems to be nothing that is immune to being presented in pink packaging during the month. Even major landmarks such as Buckingham Palace and The White House are bathed in pink

light (see [http://m.theatlantic.com/health/archive/2012/10/Sikka, 2012](http://m.theatlantic.com/health/archive/2012/10/Sikka,2012)). Whilst my participants told me that they think this is good on the one hand for raising awareness, on the other hand some of them reported that extensive media coverage could be problematic as it provided a constant reminder of what they had been through. As was discussed in the introductory chapter, media coverage of breast cancer influences both the way that women perceive their experiences and the way that they are treated by other people. I will return to this topic in chapter 7.

Need for support after treatment

The ongoing fear of recurrence perhaps explains why some participants reported that they felt abandoned at the end of their treatment. For example, Viv told me:

I went a year after that and she said 'oh I don't really need to see you anymore'. You just have your mammogram once a year. You don't actually see anyone. You just have your mammogram and get the results. So that's all now. So you do seem to be like chucked out; you've had your treatment that's that! It would be nice to be able to see someone. Even if it was just once a year just if you've got little worries or things.

Viv was one of many of the participants who told me they would like to see someone so they can talk over any worries they have. Instead they reported being left feeling abandoned. Allen et al (2009) and Arnold (1999) reported similar findings in their studies of people's experiences after treatment for cancer. Arnold argues that people can become emotionally reliant on their doctors; therefore the cessation of treatment

can represent a crisis in some cases. In the current study, not only did some participants report a need for physical reassurance, some also expressed a wish for psychological support. I return to the case of Barbara D who was 5 years post treatment when I interviewed her. She told me that she no longer had the opportunity to see the oncologist who had treated her and expressed her ongoing concerns:

Even after you've erm, it's all settled down. Because things are still going round in your head that would be nice to actually get out. So the first sort of 2 or 3 years, after that really. When you get to that stage. My oncologist is great but because I'm on the road I'm on he doesn't really want to sit down and talk to me because he's got people who are, you know, which I understand. But you would benefit from talking to somebody. Somebody who knows how your mind works. And who has worked with women so they know what happens to women.

Barbara was expressing a need not only for 'somebody who knows how your mind works' by which she is presumably referring to a psychologist, but also somebody who 'knows what happens to women'. She seems to be mourning the relationship she had with her oncologist who 'is great' but who has patients who are currently ill who take priority over Barbara who is on 'the road' she is on, presumably the road to (expected) recovery. For Barbara this loss of medical support seemed to coincide with a loss of social support, since later in her narrative she talked about how she had enjoyed being 'fussed over' as will be discussed in chapter 7. It seems that this is not an unusual reaction. For instance, Ward et al (1992) surveyed 38 women before, during and after treatment for

breast cancer about their reactions to completing therapy. The findings revealed that, although they were pleased to have finished, 30% of them reported that they were distressed by the termination of their treatment and lamented what they saw as a loss of their 'safety net', which increased their sense of vulnerability. The need for continued support was also commented on by 51 year-old Wendy Y who works as a nurse manager at the hospital in which she was treated for breast cancer:

[We need to] have that net when things, you know, when something has happened to us, to catch us a bit. Don't assume you know you've gone in, you've had the op and everything's fine afterwards. Cus you know not everybody's in a situation whereby they've got support.

The type of 'safety net' that Wendy is referring to seems often to be provided by breast care nurses. This is how Catherine described the breast care nurse who was assigned to her during her treatment:

My nurse..was brilliant. Really good, really clear. Any questions I'd got she was very focussed. And she would contact me pretty much after every chemo so I was very, very supported by her.

In the UK, breast care nurses remain available for women to contact with questions or concerns even after formal treatment has ended. Although the participants were aware that they could contact their breast care nurse at any time they seemed reluctant to do so. For example, Maggie told me about having to request a new prosthesis:

I had to ring up the breast nurse and I was thinking maybe I shouldn't be doing this 4 years down the line, I'm fine now um but when I rang them and said you know 'I need a new one because it's beginning to give way now' they were absolutely fine. So I think you sometimes wonder if you should be getting in touch with them quite a long time after but that, that's fine.

Maggie described herself as 'fine now,' unlike many participants who were less confident about their health status. It seems that because Maggie does not view herself as ill, she feels that other women (who are ill) should take precedence. Bury 1991:457 argues that people such as Maggie feel that they are now in a different category of being 'successfully treated' and therefore have used up their allocation of care. Bury (1991) argues that new crises can arise after 'successful' treatment as a result of being unable to access information and support and that this may be as difficult to deal with as the condition itself. This crisis has been highlighted in recent press coverage of cancer survivorship. Ciaran Devane, chief executive of the leading UK cancer support charity Macmillan, was reported to have expressed concerns that increasing numbers of people are having to deal with ongoing emotional and physical effects of their cancer, long after treatment has finished. Devane argues that the current system in the UK is 'woefully inadequate' at meeting the needs of cancer survivors (Atkins, 2012). In contrast, an Australian study of specialist breast nurses (Jiwa et al, 2010) describes how women have annual consultations following treatment for breast cancer. Jiwa et al argue that the sessions with specialist nurses which address both physical and emotional concerns, are pivotal to helping women to adjust to the biographical disruption of

having a life-threatening illness and the consequences of treatment.

DCIS

Maggie's more positive attitude may be because she was 6 years post treatment for DCIS. At another point in the interview, Maggie told me that she considered herself 'quite lucky' because she had not had to have chemotherapy or radiotherapy, but 'just' a mastectomy. Similarly, Breaden (1997) found that 'luck' was a recurrent theme in her interviews with six women who had been treated for various cancers. She argues that there is an expectation that they are 'lucky to be alive' but that can make people feel unable to share any worries or concerns lest they be thought of as ungrateful.

There seems to be considerable ambiguity about the seriousness of their illness amongst the participant's narratives, especially when they compared themselves to other women. This was particularly noticeable in women who, like Maggie, had been treated for the non-invasive form of breast cancer which is called ductal carcinoma in situ (DCIS). There has been considerable speculation in the media about the level of risk posed by DCIS with some suggesting that if left alone it will not become life threatening. For example, McPherson (2010:233), writing in the *British Medical Journal*, said that 'half of women with DCIS detected will develop invasive disease..[but] treatment can be withheld only when the prognosis is more specific than it can be now.' In the current study, various difficulties seem to have arisen as a result of this ambiguity. For instance June reported that her daughter's claim for critical illness insurance had been denied

because DCIS is not classified as life-threatening. She told me, 'Ooh she was livid! She's still mad now! [laughs] you should talk to her about it.' Another participant, Martha, seemed to still be trying to reconcile her mixed feelings:

You've got this very contradictory information, and ..the thing that got me ..was the absolute poor communication. You've got no information, there's no explanation, 'this is DCIS', it's a phrase you've never heard before. 'Pre-cancer', something else I'd not come across before. It's not cancer so why are you doing this? It doesn't make any sense. 'It's not urgent but you've got to take the first surgery possible'. You can't put all that in your head together, it's really difficult.

Martha expressed how distressed she was to be given scant and contradictory information about her health condition. This difficulty in reconciling the conflicting information was also highlighted by Wendy Y who had a partial mastectomy and reconstructive surgery to both breasts after being diagnosed with DCIS:

I think there's a lot of confusion. I mean one minute you're being told you've got cancer and the next minute it's all, 'well it's non-invasive' and it's all a bit woolly. And, and it is. And the thing is, we don't know do we? We don't know whether we should be doing surgery on these women.

Wendy's comments illustrate how the uncertainty surrounding DCIS can be difficult to cope with when they have had a breast removed as a result of this diagnosis as well as the

difficulty of treatment choice in the face of uncertainty⁶.

Malaika who was also diagnosed with DCIS and had a mastectomy expressed a different set of concerns:

Because I got diagnosed with DCIS I do, when people say, you know 'oh, you've had breast cancer you poor thing' and I feel like I have to go through this long drawn-out thing, 'well yeah but it's what they call DCIS so it's actually..' and sometimes I feel like yeah, like I'm apologising for not dying, for not having an aggressive cancer, not having chemotherapy and all of these things. And um and I shouldn't really. And my breast nurse even said to me when I told her that someone had said to me 'did you really have breast cancer?' she said 'I beg your pardon?' she said 'what?' I said 'could you please explain to me because I got told I'd got breast cancer, I'd got told that DCIS is an immature cancer and it doesn't have the ability to spread but it's still cancerous.' And I said 'someone else said it's not cancer and it's just before cancer and I just don't-' and she said 'you had a diagnosis young lady and you had a mastectomy and anybody who has the audacity to even come to you and ask you those sorts of questions..' But it is my own stuff because I, I do feel [pause] apologetic actually [pause] even going down that road, saying yeah you know it's an early stage breast cancer blah, blah.

This illustrates a common reaction amongst the participants which was to compare themselves to other women that they perceived to be worse off than they were. For example, in the

⁶ Additional controversy over the benefits of breast screening has recently hit the headlines and has added to women's confusion (Pharoah, 2012).

previous chapter I described how Malaika had compared herself to a woman who had lost her hair as a result of chemotherapy and judged herself to be better off in comparison even though she had lost a breast.

These feelings were also evident even for women who had ESBC, where they did not require chemotherapy. Wendy S who had a lumpectomy and radiotherapy described to me how she felt like a 'fraud':

I did feel a bit of a fraud actually because I only had to have surgery and radiotherapy I really felt quite a fraud because I didn't have to go through chemo I didn't feel I could talk to people who had it worse than me. Because of course .. there were people who had it just after me so they were able to talk to me about what they had done and I have to tell them that I found the treatment fine, I mean there was some skin damage but it wasn't anything you couldn't cope with. .I've had nothing, it's all done and dusted.

Wendy negates her experience saying that she had 'had nothing' despite having had surgery and radiotherapy. This seems to have made her uncomfortable at being unable to relate to other women's experiences which differed from her own which she describes as 'fine'. Wendy reported that she thought that women who had undergone chemotherapy must feel 'irritated by women like her' who had not had the same amount of treatment. This is described by Wood et al (1985) as downward comparison, which means comparing oneself favourably with others who are perceived to be worse off. In the majority of the 78 interviews they conducted with women with breast cancer, Wood et al found that participants were

more likely to compare themselves with others who were worse off (downward comparison) than with either similar others or those that Wood et al refer to as 'supercopers' who appear to have thrived since being diagnosed with breast cancer. This seems to have been used here as a coping strategy for some participants.

The feelings of guilt, fear and confusion that are reported by some of the participants seem to be the result of women with DCIS/ESBC and secondary breast cancer being grouped together in terms of treatment, support and the way they are discussed in wider public. This is an important theme and a major finding of this study which will be discussed further in chapter 7 as it affects the way they feel about themselves and the way they are treated by others, as well as the support that they are willing or able to access. Wendy S. continued:

It's about being called a 'cancer survivor' and the expression 'in remission'. I don't like that at all. When someone mentioned me being in remission I thought 'I'm not in remission, it's gone!' You know, in remission sounds like it could come back. And cancer survivor well yes those people who have gone through really bad treatment I'm sure they consider themselves survivors but I consider myself someone who has had cancer and its gone.

It seems that participants such as Wendy who had not had chemotherapy seemed reluctant to be described in terms such as 'brave' or 'survivors' as they felt they had not suffered sufficiently to merit such praise. Kaiser (2008) had similar findings when she interviewed 39 women about how the survivor identity affected their breast cancer experience. She

reported that half of them rejected the survivor identity because they did not feel that they had been close enough to death to merit the label of survivor. Some further issues surrounding identity within the experience of having ESBC/DCIS will be discussed in the following section.

Identity

Previously in this chapter I discussed how some participants expressed a loss of control and agency as a result of their experience of ESBC/DCIS. I described how Wendy Y who works as a nurse manager had reported a recurring dream which seemed to represent her loss of agency. I will now describe how some participants, starting with Wendy, managed to regain some sense of control and in the process re-establish their identity. Wendy described how she had asserted her wish to have radiotherapy despite being told it was not necessary:

I'd done massive research, I'd spent hours in that medical library and all the research was saying that women do need radiotherapy. And I, I said 'I don't want to be difficult but I haven't read a research paper which suggests that you don't have to have radiotherapy after this, and I've even looked at the NICE guidelines'. And he said 'yes you're absolutely right, however in Nottingham you know we've done a lot more research' and he said 'it's proving that it's not having any more effect'. And I said 'well I feel a bit uncomfortable about that because it's not that I don't believe you, of course I believe you, I've got a lot of trust in you and I know Nottingham's at the forefront, however you know can I

just turn it round. How would you feel if you'd read all this research? As a reasonably intelligent person and yet you'd got somebody, and I'm telling you now I don't want to ever go down this road again. You know that I'd complied and everything's gone very well but I, I can't go through this experience again it it's taken its toll on me, nobody knows it has but it has'. And I was quite assertive. But I was ready when I went in because I had a feeling that might happen and he said 'I respect you, I think it would be reasonable for you to go and talk to the radiotherapy er oncologist' and um we left it at that. And it all was very amicable actually; I don't want you to think it wasn't. But erm and I didn't have to fight erm so I went to see the oncologist and he said 'I think in your position I would want radiotherapy' and, he said 'I think it's a very very reasonable request'. He showed me the letter he sent to everybody and he actually put that, he said 'I think it's very reasonable that she has it.'

It is worth considering this lengthy excerpt as it illustrates what Wendy is doing by telling me this story in so much detail. She is showing me how she was assertive by asking the doctor to consider her position 'how would you feel?' yet respectful of his opinion and seems keen to convince me that the exchange was 'amicable'. Gill (2005) studied medical interactions using Conversation Analysis and argues that whilst patients rarely overtly disagree with doctors, they are able to negotiate their treatments in subtle ways that do not undermine the doctor's authority, which seems to be the case in the above scenario. Wendy appeared to have taken control by carrying out her own research and as a result, she seems to not only have got the treatment that she requested but also won the respect of

her doctors. This is relevant given that Wendy holds a fairly powerful position in the hospital where she was treated. It seemed to be her way of reasserting her status as a 'reasonably intelligent person' in possession of medical knowledge not only to the doctors that she reports having spoken to but also to me and perhaps through her narrative, to herself.

However, other professional identities seemed to be more difficult to sustain. For example, Martha who works in a senior capacity at the university described what she saw as a threat to her professional status. Unlike the majority of the women I spoke to who told me how grateful they were for the swift treatment they had received, Martha felt that she was being undermined as she was expected to drop all her professional commitments in order to attend hospital appointments. She told me:

They **insisted** that I came back the next day for the results, and I didn't want to come back the next day. I'd got a big meeting with the academic secretary, head of the department, head of another department. It had been arranged for 10 days, it was an emergency meeting. Ah I just couldn't see how we could cancel it. But they were **really** not helpful.[participant's emphasis]

Again, the narrator seems to be trying to convince me as the listener, of her important position. Martha seems to be resisting entering the sick role as she felt her work identity was important to her. She commented afterwards that her identity had been affected by the cancer experience:

You're having to change all your ideas of what you can do, which then affects ideas of who you are, do you

know what I mean? I mean I was what, 53 at the time? You sit in the waiting rooms and the vast majority of the women there are older than you. There were people there in smart suits looking as if they were going somewhere, that had a career, stuck out like sore thumbs. So as much as anything else it was the notion of identity and who I was.

It seems that Martha felt out of place in the hospital because the other patients were so dissimilar to her. Not only were most of them older than her (as was discussed in chapter 4) but she judged them to be in a different social position. Interestingly she posits that the few women who were in 'smart suits' looked like they were 'going somewhere' and she assumed they (like her) had a career. Presumably she felt that the others were content to spend their time in the waiting room, or at least that it was less disruptive for them. However, being restricted in terms of what she could do, i.e. control over her time, seems to have affected Martha's identity as a career woman. This illustrates the loss of status that can be associated with liminality (Turner, 1969).

The 'cancer identity' was never clearer to me than when I attended a breast cancer support group as part of my effort to recruit participants. The meeting was held in the waiting room of the clinic where I was treated. There were about 20 women who were mostly older than me, and our chairs were arranged in a semi-circle. A breast care nurse, who was the invited speaker, stood at the front of the room. Here is my reflection from my personal research diary:

They said that the evening would take the form of a question and answer session and asked us to briefly

introduce ourselves and ask any question which would be written on a flip chart. Each woman introduced herself in turn by saying her name and how long it was since being diagnosed. This hadn't been asked for. It seemed a contrast to the usual settings for introducing yourself in this way when you would say the name of the organisation you were from, or your role within an organisation. It underlined that the common thread linking us all was that we had all been diagnosed with breast cancer and in that setting, that was what defined us. (Breast cancer support meeting 20/4/10)

One of my participants however was resisting the cancer identity. Karen, who had no hair when I interviewed her, because she was still undergoing chemotherapy said:

You can't disguise I've got cancer you know, it's um, but I think that's why I needed to go back to work. It's about, you know, it's a part of me, it's a **big** part of me at the moment but it's just a part of me, its part of who I am. (Participant's emphasis)

Karen reported that she had kept working in order to maintain her identity and not be taken over by breast cancer which constituted just 'a part' of it. Similarly, when I applied for the University scholarship to do the MA in Research Methods I deliberately did not mention that I was undergoing treatment for ESBC. As far as I was concerned, cancer had only been part of my identity for a few months and I did not want to be treated any differently by those who were considering my application. For me, this potential new chapter in my life represented leaving the cancer identity behind. Nevertheless, I was happy to retain aspects of it for my own purposes,

specifically to help me to conduct the current research, thus regaining some agency over the cancer identity. Similarly, several of the participants retained some aspects of the cancer identity in order to identify with, and support, other women going through a similar experience. I will return to this topic in chapter 7.

There were other examples of the interesting ways in which people were able to do identity work through their illness narratives. For example, Sam seemed to be reasserting her identity in this description of how she had insisted on having a CT scan to check for any signs that her cancer had spread:

They weren't going to give me one. But I did say after I'd finished all my treatment, I ended up saying to my consultant, 'it's alright for you to sit there and keep saying no, no, no but you're not the one sitting there as a single parent. She's already lost her dad' because he died after I left him um I said 'so to lose me as well' I said 'I need to know, I need to know the score. You know, it's easy for you to sit there and make decisions but you're not the one in my shoes'. So she did put me through for a CT scan and they said everything was fine.

In this description Sam seems to be constructing herself as assertive as she reports challenging the doctor's authority rather than accepting it passively as circumscribed by the sick role. This seems to reinforce the centrality of single parenthood to Sam's sense of identity and highlights how being a single parent mediated her experience of being ill. Similarly, Wilson (2007) describes the enduring facet of identity of being a mother as most pertinent for the women she interviewed about the effects of HIV infection on identity.

Again, Sam is talking in terms of fairness – her daughter’s father had died so it would be unfair if she was to die as well, leaving her daughter orphaned whilst undeserving of this fate. Sam’s primary identity as a mother appears to remain constant, despite the disruption to almost every other facet of her identity as discussed earlier in the chapter. Other participants who had dependent children at the time of their treatment also reinforced their identity as mothers first and foremost despite their experience of biographic disruption. One of those who fell into this category was Catherine who reported that her main concern throughout the experience was the effect on her family, particularly her son. This will be taken up in more detail in chapter 7. However, Catherine also seemed to have used the time when she had been removed from everyday norms to reflect on what was important to her. Catherine described how she felt after recently completing treatment which included surgery, chemotherapy and radiotherapy:

You have to take yourself anew don’t you? You definitely do not feel in any shape or form the sort of person who you were before. You’ve been chucked up in the air and you come back down again and everything’s different, it feels to me.

Catherine’s narrative has clear parallels with Turner’s (1969:103) description of the liminal subject as a ‘blank slate.’ In terms of identity construction, it suggests that for some participants the experience of ESBC/DCIS can also mean creating a new ‘self’ and not being the same person. This is in contrast to others who expressed a need to assert their pre-cancer professional/parental selves. It seems that even though so far I have highlighted the negative aspects of

liminality, it is not necessarily all bad news. Turner (1967:106) argues that liminality can be seen as an opportunity for reflection, existentialism and growth. He describes how hitherto taken for granted norms and assumptions are questioned during the period of liminality and that there is a certain freedom to 'juggle with the factors of existence'. Whilst not denying the horror and sadness of their experiences it seems that for some participants the post-treatment period can also be a time of positive change. This is how Catherine described her change of philosophy, using the metaphor of Amazonian women to reinforce her point:

It makes you focus, getting breast cancer. And those Amazon women that were very focussed on their shooting, it makes you, well it's made me decide what's worth bothering about and what's not worth bothering about.

The metaphor of Amazonian women is an interesting one because they are a tribe of women who are said to have voluntarily removed one breast in order to improve their skills with a bow and arrow. Castelnuovo & Guthrie (1998) argue that for the Amazons, mastectomy was an act of empowerment. It seems that being faced with her own mortality has altered Catherine's outlook and she reported that she had used the illness experience to examine her life and decide what was worth spending her time and energy on. However, such changes are contingent on circumstances as is particularly apparent in Sam's case where the stagnation of her situation had prevented her making desired changes, as previously discussed. Nevertheless, Sam had used the agency she had in order to volunteer as a patient ambassador. Changes which seem to have arisen as a result of my

participants having had their lives disrupted by a diagnosis and treatment for ESBC/DCIS, will be discussed in chapter 7 in terms of meaning as consequence (Bury, 1991).

Chapter summary

In this chapter I have extended Bury's (1982) argument that the diagnosis and treatment of ESBC/DCIS can be disruptive to lives and identities. I have suggested that disruption also occurs upon the cessation of treatment where participants are no longer classified as ill, but neither do they feel able to describe themselves as healthy. This state of ambiguity and uncertainty has been compared to the state in rites of passage described by social anthropologist Victor Turner (1967, 1969) as liminality where subjects are 'betwixt and between' states in which they can be classified. Although this comparison has been made in previous studies of illness experiences, particularly cancer (Little et al, 1998), the current study benefits from locating the experience of being diagnosed with and treated for breast cancer within women's life narratives. This can provide insights into some of the reasons why women react differently to biographical disruption and liminality such as their type of cancer, time since diagnosis, marital status and the importance to them of retaining aspects of their identity such as professional status. In addition, previous studies have tended to concentrate on the ambiguous nature of liminality whereas the current study considers other facets of the liminal state such as sexual continence, silence and passivity. This can help to explain how and why women react as they do to this life-threatening illness and how they negotiate living in a 'new normality' (Mukherjee 2011b). This study also highlights the particular challenges faced by women

who have had ESBC/DCIS such as the risk of recurrence and the long-term implications of having surgery to the breast(s) in terms of self-concept and the impact on current and potential relationships. This gendered consideration of biographical disruption and liminality is a unique contribution of the current research since previously these concepts have only been applied in combination in studies of prostate cancer. These aspects of the experience will be discussed further in the following two chapters which consider the nature of a 'new normal' in respect of bodies and relationships respectively.

Chapter 6 Living with a new normal part

1: Body

Introduction

So far, I have explored women's experiences of the disruption caused by the diagnosis and treatment for ESBC/DCIS drawing on Bury's (1982) theory of illness as a biographical disruption. Chapter 4 considered the immediate disruption caused during treatment as reported by the participants where it was seen how a diagnosis of ESBC/DCIS sometimes disrupted the sense of self as healthy. In bodily terms I discussed the impact of side-effects of treatment, specifically the way that loss of hair marked the transition from healthy to the sick role. Chapter 4 also incorporated Bury's (1991) theory of meaning as significance, looking at the ways that participants came to understand and make sense of the aetiology of their cancer within their personal biographies. The theme of disruption was continued in chapter 5 to consider the transition from the sick role to a state of liminality which was marked by uncertainty, ambivalence and silence.

The current chapter will look at the implications of permanent disruptions to bodies which Bury (1988) refers to as meaning as consequence. Embodied changes are a crucial aspect of the illness experience because, as Kelly & Field (1996) argue, they influence identity and social relationships, as was discussed in chapter 4. Therefore I will draw on the data with an emphasis on the particular challenges faced by women after treatment for ESBC/DCIS including the impact of bodily changes on

intimate relationships. This will be continued in the following chapter with a further exploration of the consequences of breast cancer in respect of relationships, including the consequences of having a stigmatizing illness within wider society.

Breast cancer is more than a medical complaint because it can affect women on a social as well as a medical level. Ferguson & Kasper (2000) argue that when breast cancer is viewed through a social lens rather than from a solely medical perspective, the loss of a breast is seen as far more than the loss of a body part. This is because breasts play a major role in societal expectations for women to be 'physically attractive, sexually inviting, and maternal' (Ferguson & Kasper,2000:3). The impact of breast surgery therefore is primarily concerned with how it affects women's identities and their presentation to other people (Goffman, 1969), be they intimate partners or the wider public. In this chapter I will be considering the importance of breasts to women's sense of self, identity, and femininity as well as the role of breasts in intimate relationships and the pressure to appear 'normal' which impacts on the process of treatment decision-making.

This chapter will begin with an examination of the permanent changes resulting from treatment for ESBC/DCIS and the consequences of these changes on the participants' lives. This will encompass a particular emphasis on the meaning and importance of breasts as reported by the participants. I will then develop this theme to look at how changes to their bodies have affected participants' feelings of confidence and sexuality and the consequences for current and potential intimate relationships. The second part of the chapter will focus on reconstructive surgery and the treatment decision-

making process including a consideration of what is meant by 'normal' in this context. Finally I will consider whether a 'normal' body can ever be restored or whether the post-treatment period involves coming to terms with a 'new normal' body.

Consequences for the body

Just over two years after I had a mastectomy, my lymph nodes cleared from one armpit and breast reconstruction, this is what I wrote in my research journal:

Although I now feel well and my life is no longer disrupted by weekly trips to the hospital, every time I undress I am reminded that I have had breast cancer. I have a scar running from my spine to my breast and further scars beneath each armpit. I have several tattoos that the radiographers used to direct the rays for the radiotherapy treatment. My eyebrows have never fully grown back. I have no left nipple, just a circle of skin transplanted from my back. I have no feeling along the length of the scar or under my arm. I can never use a razor because I would not know if I cut myself and an infection could result in lymphoedema, a painful swelling of the arm. Every day I must exercise my arm to stimulate the lymphatic fluid and I must protect my arm at all times from injury, excessive heat and the sun. My reconstructed breast has no sensation but it means that I can wear a swimsuit to take my boys swimming without people staring at me. Before I had the mastectomy I had never had surgery. It shocks me that

I am scarred in this way. (Research diary 4th March, 2010)

This extract reveals how bodily changes continue to impact on my life and self-image, long after treatment has ended. All of the things I described will remain with me for the rest of my life and this lived experience seems to characterize embodiment. There are rituals that I go through; taking a daily tablet, moisturizing my skin along the scar lines and also doing the exercises to prevent the buildup of lymphatic fluid. All of these aspects of my experience confirm Bury's (1982) view of illness as biographical disruption. These elements of changed appearance and behaviour show how my life continues to be disrupted as I learn to live with my 'new normal' body.

In chapter 4, I highlighted the disruption caused to women's bodies during the treatment for breast cancer. This included a discussion of hair loss which was one of the more immediate bodily disruptions which signified their transformation to cancer patient. Although this was reported to be a traumatic experience which impacted on the affected participants' identities, it was nonetheless a temporary side-effect of treatment. By the time I interviewed them, all but one of the women who had lost their hair through chemotherapy had completed their treatment. Although their hair had grown back, sometimes it looked different to before. For example, Barbara D told me that she used to have straight hair:

I always say they put me back together upside-down. Because my head was curly but all the other parts of me wasn't! [laughs] My eyebrows haven't come back; I used to have quite bushy eyebrows.

At the time of interview, most of the participants in the current study had left the sick role behind in the sense that they had returned to their normal roles and responsibilities. However, there were lingering reminders in the aftermath of the treatment of what the women had been through. The quote above suggests that Barbara had to adjust to the disruption caused to defining features of her appearance. Others reported that they were experiencing menopausal symptoms such as hot flushes as a result of hormone treatment. Some had visible reminders of radiotherapy treatment such as Ruth who described burn marks:

It left a great sort of like someone had put an iron, mine was sort of triangular, like someone had put an enormous iron on my chest and the top of my arm and left it there.

Ruth also told me that she suffered from lymphoedema and reported continuing numbness and weakness in the affected arm which had meant that she had to give up pottery, which she loved. Ruth has to wear a compression bandage and told me:

It's so uncomfortable at the end of the day I'm desperate to get it off, it's a great joy to pull this off at the end of the day. So it's a small thing I really shouldn't complain at all.

This reticence to complain about the consequences of treatment was a common theme amongst the participants. It may be because they felt it was ungrateful to complain when they know that other women have died as was discussed in the previous chapter. Another explanation is that it may be related to the passive sick role where the medical system has

control of their situation. McParland et al (2010) had similar findings in their study of people suffering from chronic pain and argue that their participants felt 'compelled to express gratitude' in order to continue to get their needs met, which again was mentioned in the previous chapter. In another example in the current study, Martha reported that she had become so fed up of the small tattoos that had been used in the radiotherapy treatment, that she had paid to have them removed by laser surgery:

I decided I couldn't bear the tattoos any more. I thought I might feel better about myself if I lost them.. they were just dots.. I just thought this is ridiculous, this is really ridiculous, they're just dots, you don't need – I did! [laughs]And it's stupid but it seemed to help.

Although acknowledging that they had become important to her as they seemed to remind her of what she had been through, Martha seems to feel the need to justify her desire for the tattoos to be removed, as though she was being particularly vain by worrying about 'dots'. It shows how they had a symbolic meaning beyond being just dots which Martha wanted to erase, although she chastised herself for doing so.

However, the lingering reminders of their experience that were not so easily erased were as a result of surgery to one or both breasts and this was the main cause of disruption reported by my participants. After immediate concerns for saving their life had been addressed, the participants were living with the repercussions of their treatment. Breasts are symbolic of femininity and motherhood, particularly in Western society, and women are judged on their size and shape. Consequently, cosmetic surgery to reduce or more

commonly, augment breasts, has become a lucrative industry. In her essay 'Breasted experience: The Look and the Feeling' Iris Young (1990) highlights the social importance of breasts and argues that the appearance of breasts can affect women's body image, self confidence and sexuality. Therefore failure to conform to societal expectations of appearance can have implications ranging from embarrassment to depression.

Although breasts are generally hidden, sometimes women are in situations where people may see them unclothed. In the current study, Maggie told me about her experiences since she had had a mastectomy:

I don't like looking at myself in the mirror now, at least not that part. I'm very conscious of even my husband or even my kids seeing it..or anybody else for that matter. I mean I would never go into a changing room where there were other, you know communal changing room somewhere like that. And I would never - I mean like a friend was having for her 50th birthday she was having a group of friends to go to one of these spa places for the day and I declined because I just didn't - although they knew, I just didn't feel confident about it. You know moving around in a bathrobe or something. So that's probably the only time it bothers me. On a day to day basis it's not an issue at all.

Maggie seems to view her body with a certain amount of shame. Bartky (1990:86) argues that 'shame is the distressed apprehension of the self as inadequate or diminished'. Even though Maggie said her friends were aware of her surgery, her comments suggest that she fears that this inadequacy 'may come suddenly and horribly to light' (Bartky,1990:86).

Although Maggie was able to ignore her bodily changes most of the time, she acknowledged that she felt self-conscious and therefore changed her behaviour to avoid uncomfortable situations. Bury (1982) describes this as disruption because previously taken for granted activities now required planning in order to conceal the results of surgery. Maggie's experience highlights the permanence of this disruption stating more than once that she would 'never' allow her body to be revealed in public. This echoes Young's (1990) argument that for most women, the breast is heavily implicated in their identity therefore its loss can be experienced as extremely traumatic. Women can be emotionally distressed by a mastectomy, sometimes for many years afterwards as in the case of 72 year-old Jean. In chapter 4 I described how Jean repeatedly returned to her reactions to her diagnosis and mastectomy 29 years previously. Her narrative was scattered with phrases such as 'frightened', 'horrendous', 'nightmare' and 'hell' when describing what she had been through. Jean told me how she dealt with the ongoing reminder of her apparently traumatic experience in her everyday life by positioning her mirror in such a way that she was unable to see below her neck:

I don't look at it and I never, in the bathroom there's the mirror there, it's a bit higher cus Ken's taller and I never ever looked at them, just totally ignored it and got on with it. I'd got to get back to doing what I did.

It seems that Jean felt that the best way of getting back to 'normal' (i.e. 'get back to doing what I did') was to ignore the visual reminder of what she had been through by taking practical steps in order to avoid seeing herself when she was undressed. Jean's body bore embodied reminders of her trauma, which is an illustration of Roy's (2009) argument that

bodies are the repository of memory. Roy interviewed female political prisoners who were victims of torture in Naxalbari, which revealed that their trauma was literally inscribed on their bodies which were permanently marked as a result of their ordeal. For some of my participants, the sight of their body, which had been mutilated by surgery, reconfirmed their cancer experience and, like Roy's participants, 'the body bears witness to trauma' (2009:152). However, Barbara D was a little more optimistic:

I can't believe that I've had it now. I can't believe that it happened to me. But I've always got that reminder. I went through all that. Me! I did it! You know in some ways it's something to be proud of in a funny sort of way.

For Barbara, it seems the sight of her body which has 'that reminder', is affirmation of how she got through a traumatizing episode and she expresses triumph, exclaiming 'me! I did it!'

The extent to which participants were traumatized or accepting of their post-treatment bodies seemed to depend on the way they perceived their breasts in relation to their body image and relationships. The loss of the breast(s) meant that the participants reflected on what their breasts meant to them and to various extents, affected their ability to adapt to life after breast cancer and their 'new normal' as will now be discussed.

Meaning of breasts

The ways that my participants talked about their breasts suggested that they imbued them with different meanings

which were reflected in the significance of the loss of part, one, or both of them. That, as well as their relationship status and age, also appeared to influence their decision about whether to have reconstructive surgery. This contrasts with the attitude which, according to Wilkinson & Kitzinger (1993), is endemic in medical culture where the husband's sexual needs seem to be paramount when considering the impact of surgery to a woman's breast(s). In a feminist critique of the treatment for breast cancer, they argue that this reflects the cultural view that the primary function of women's breasts is for male sexual pleasure and that reconstructive surgery is promoted for this reason.

The meanings that different women attach to breasts was studied by Langellier & Sullivan (1998) who isolated references to breasts in the narratives of seventeen American women who had been treated for breast cancer. They identified four interrelated and overlapping clusters of meanings attached to the term breast which were described as follows:

- **'Medicalized'** In the medicalized view, Langellier & Sullivan (1998) argue that the breast is decontextualized from the rest of the body and the woman's life. It is seen as unconnected to feelings of femininity and sexuality and as an expendable body part, particularly when the alternative to losing the breast is loss of life.
- **'Functional'** According to Langellier & Sullivan (1998) the functional view of the breast is similar to the medicalized view in that there is less emphasis on what it looks like and the emotional attachment to the breast.

The functional breast is seen in terms of what it can do. In addition to being a major part of the upper body, affecting movement and strength, it refers to the more obvious function of breast feeding. Participants in Langellier & Sullivan's study talked about their breasts in functional terms when describing activities that were now difficult to perform, or how there were restrictions to what they could wear to avoid showing scars or prostheses.

- **'Gendered'** Langellier & Sullivan (1998) argue that the meaning of the breast as gendered is the most prevalent view in Western culture where breasts are a public sign of femininity and sexual desirability. Bartky (1990:77) argues that 'to have a body felt to be "feminine" ...is in most cases crucial to a woman's sense of herself as female and , since persons currently can be only male or female, to her sense of herself as an existing individual' [original emphasis]. Consequently, women undergoing surgery to their breasts can experience the fear of not conforming to cultural norms of femininity as a threat to their identity as a woman, as well as to their intimate relationships.
- **'Sexualized'** this final category is related to the gendered view because it refers to appearance and attractiveness. However it is not just about the look of the breasts but also the feel of them to the woman herself and to other people. In this category, Langellier & Sullivan (1998) argue that feeling sexually desirable is about more than the breasts, because it incorporates thoughts, feelings and emotions.

From their perspective in health communications, Langellier & Sullivan (1998) conclude that it is important to understand the various meanings attached to the breast by different women in order to help them to adapt to life without it. They recommend allowing women to explain the meaning of their breast in their own words rather than assuming that every woman feels the same way and that this is the best way of capturing the complexities of the experience of breast cancer. However, a drawback of their research was that although the sample contained women aged between 32 and 64, there were no indications of the ages of the women in the analysis. Therefore it was difficult to attribute different meanings to different age groups. For example, Langellier & Sullivan state that not all participants mentioned sexuality but it was not clear if this was age related. In the current study I was surprised that most of my participants spoke quite candidly about their sex lives, particularly when it was women who are older than me, but that perhaps reveals my own cultural prejudices.

More recently, Fallbjork et al (2012) studied the narratives of 15 Swedish women aged between 39-59, who had undergone a mastectomy due to breast cancer between 4 and 5 years previously, to explore their feelings towards breast loss and reconstruction. They discovered three main themes surrounding the topic of mastectomy. The first group who were mainly older and in long-term relationships described the loss of their breast as 'no big deal', whereas the second group who were younger and single, experienced mastectomy as a 'loss of self'. The third group occupied a middle ground which was described as 'a wounded femininity'. My participants drew on some or all of the categories identified by Langellier &

Sullivan (1998) and Fallbjork et al (2012) at various points in their narratives, sometimes simultaneously and sometimes in contradictory ways. Often, the meaning of the breasts appeared to change over the course of the narrative. For example, the medical view was most commonly held immediately after diagnosis where issues of sexuality and femininity were not reported to be as important as survival. Consequently some of the participants reported that their immediate reaction to their diagnosis as a wish to have their breast(s) removed completely. For example, Gabrielle who was 42 at the time of diagnosis with daughters who were aged 6 and 7, told me:

My reaction was 'that's fine, just cut it off, just take it off, that's fine'. And he said 'well there are a few other things that you might be offered, breast reconstruction'; you know 'there are different breast reconstructions'. But I said 'no, no just remove it'..I couldn't take it in, the other options and everything. Because my reality was..' I can't die, I've got two daughters' and that was the only response he got from me when he told me the news it was , 'I can't die I've got two young children'. And it then became all about how, my children really.

Gabrielle's comments illustrate how survival was prioritized over all other considerations. Although this was the case for all of the participants, it was most often expressed by women with dependent children. However, it seems that the passage of time had enabled some of the participants to reflect on what it meant to actually live without a breast. For example, Sam reported that:

When I first had the mastectomy and I came round, I was lying in the hospital bed and my way of dealing with it was thinking 'well its only a bit of flesh, you're here. And just think about all those kids, they get meningitis and have to have their arms and legs amputated. This is nothing in comparison.' And that is what I thought. But obviously the longer it's gone on the more I realise that it has had a big impact on my life. Not the cancer diagnosis, because obviously that's something you do learn to live with, the fact that I am here and I've gone through the treatment treadmill and that's great. It's that it does have a hell of an effect on me as a woman.

Sam's initial reaction to her mastectomy was seeing it as a medical necessity; therefore she was adopting the medical discourse by prioritizing her survival over issues surrounding the cultural and emotional importance of breasts. However, after finishing what she describes as the 'treatment treadmill' (or 'that conveyor belt' as another participant described it), Sam's perception of her lost breast as medicalized seems to have given way to a different view; one that is imbued with emotions as she realized how the loss of her breast had impacted on her sense of herself 'as a woman'. As both Langellier & Sullivan (1998) and Fallbjork et al (2012) suggest, the meanings attached to breasts can alter over time and also within women's on-going life narratives.

In contrast to Sam, Nina commented that she attached a lack of importance to her breasts:

I don't have a problem with that; just having one breast doesn't really bother me. At the end of the day people lose legs don't they? And arms and whatever, it doesn't

change you. I had a hysterectomy but it doesn't change me as a person.

Nina seems to be rejecting the idea that losing a breast could impact on her sense of self although she later seemed to contradict herself when she was telling me why she wanted to have reconstructive surgery, as will be discussed later in this chapter. Additionally, Nina's comment that her hysterectomy had not changed her as a person indicates that she feels there is more to being a woman than possessing female body parts. Langellier & Sullivan (1998) argue that this way of describing the breast is medicalized because it is not associated with femininity or sexuality. Nina is suggesting that she considered her breast to be a non-essential part of the body and therefore, similarly to Sam, she reported that she felt lucky in comparison to people who lost an arm or a leg. This was a frequent comparison made by participants and further evidence of the coping strategy of downward comparison (Wood et al, 1985) which was discussed in chapter 5.

Karen, who was interviewed six months after having a mastectomy also played down the importance of her breast:

I see it like, it's done its job over my 20s and 30s whatever you know, and it doesn't define who I am.

By describing her breast as having 'done its job' of breastfeeding her children, Karen is referring to the functional view of her breast as a way of de-emphasizing the significance of its loss to her identity. Karen is also resisting being defined by the appearance of her body, although for some participants their new body shape was felt to be a radical change. For instance, Catherine described how her body image had been disrupted by her mastectomy:

It was sort of like having grown up as a woman and then all of a sudden look down and see your tummy still again! [laughs]. Look like a little boy on one side [laughs]

This extract seems to illustrate the notion of the gendered breast, supporting Young's (1990:191) argument that 'breasts are the most visible sign of a woman's femininity, the signal of her sexuality'. It seems that Catherine's view of herself as a woman which had developed since puberty had been disrupted by surgery. She reported that she now resembled 'a little boy', suggesting the importance of breasts to a feminine appearance. Hallowell (2000:165) studied the case-histories of six women undergoing prophylactic mastectomy⁷ and argues that 'femininity is, at least in part, dependent on having a particular type of body – a body with breasts' and therefore the removal of a breast can threaten a woman's identity.

This was not the case however for another participant, 63 year-old Andrea, who explained why she felt that breasts were not important to her sense of womanhood:

For me being me, and this is another issue about me being a lesbian, I don't wear women's clothes, I look like this all the time. But for me it wasn't that different, it wasn't an appearance issue. I feel better, like this. No extra surgery. It's quite a major I've lost a part of my body and I was quite big breasted so I've got extensive scarring but I'm fit and well and I'm alive.

Andrea is acknowledging the major changes to her body now that her large breasts have been removed. She has to cope

⁷ Prophylactic mastectomy is where women opt to have their breast(s) removed when no cancer is present, in order to reduce their risk of developing breast cancer. Usually this is because they have been alerted to a genetic risk.

with the scarring but as her breasts were apparently never important to her self-perception as a woman, she seems to be coping with her loss, particularly when compared to the importance of being alive and well. It seems that Andrea's identity was affected to a lesser extent by the loss of her breasts because unlike some other women, she did not need to conform to gendered norms as she had adopted a non-feminine appearance as part of her lifestyle, even prior to surgery. The way she described it to me, her preference to dress in men's clothes anyway meant that breasts were not crucial to her particular gender performance in the same way as for some of the other participants.

The eldest of my participants, Barbara PK, who was 80 and widowed, told me that losing her breasts was not a major issue:

I'm not bothered at my age I mean when you get to 80 you're not wanting to er [laughs] you know chase round the fellas sort of thing! [laughs]

Even in this lighthearted response, Barbara is underlining the role of breasts in perceptions of heterosexual attractiveness and also reflecting the cultural view of sex becoming less important as women get older. In another example, Joy seemed confident that her relationship with her husband would not suffer unduly because of her mastectomy:

Well I've been married blooming 40 odd years now, you know your body does change anyway I mean I've never had, I've never been like, I wouldn't want to be like bloody Jordan!

The above comments show that Joy seems to accept as inevitable that her body would change and that she had never desired or been able to aspire to topless model (Jordan) standards anyway. In this respect she is similar to the first group of participants identified by Fallbjork et al (2012) for whom breast loss was not seen as a big deal. They accepted that their body would naturally change as they grew older with one participant commenting 'you actually should have some rips in your sails' (Fallbjork et al (2012:E46). Joy is also alluding to the role of breasts in heterosexual desire which she seems to suggest has become less important after being married for so long. Similarly, 59 year-old Ruth, who had a double mastectomy, told me:

I'm not that bothered. And if it bothered him I think that would be slightly worrying, it would indicate to me that there's were problems in the relationship if that was all that was attracting him, you know, but I don't need them anymore.

It seems that Ruth regarded her breasts as primarily functional, with her comment 'I don't need them anymore'. Whilst she acknowledged that breasts are part of a woman's attractiveness, she reported that she felt that her marriage was based on more fundamental values. That breasts are not necessary was highlighted by June, who was 63 when she was diagnosed. She told me:

I says 'it's definitely cancer duck and I'm going to have a mastectomy.' I says 'will you still love me?' [laughs]
He says 'do what you want duck. You know that.'

The term 'duck' is used locally as a term of endearment. It seems that for June, as with many other participants, their

loving relationship transcended the physical aspects. Nevertheless, breast reconstruction is routinely offered to women and there are no restrictions on age. However, Joy told me that she had decided that she did not want further surgery and that her age was a major factor in her decision:

If you think I'm coming in here again at my age [laughs]
I mean if I'd have been 30 it might have been a
different kettle of fish but at 63 there was no way I was
going in there to be reconstructed.

Joy seems to be suggesting that body image was more important to her when she was in her 30's than now and that she is not prepared to undergo major surgery again. It is noticeable that all the women quoted above were over 60 years old, which was similar to the findings of Fallbjork et al (2012). The first group of women in their study described the loss of their breast as 'no big deal' which the researchers attributed to the women's age (the average was 60 years) and their relationship status (all of the women in the group were cohabiting). In this respect, their participants were much like Joy, Ruth and Barbara, whose attitudes reflected this view that their breast was not crucial to either their view of themselves as women, or to their sexual relationships and consequently they saw no point in undertaking reconstruction. However, this is not a necessarily always the case with older women. For example Neises et al (1994) measured various facets of quality of life including sexuality, body image and femininity in 81 women after they had a mastectomy to treat breast cancer. They found that the 39 women in the study who were aged 60 or over had significantly lower scores than their younger counterparts and reported feelings of incomplete womanhood and feeling less physically attractive. They

concluded that some women suffered as a result of losing a breast, whatever their age and this was borne out in the experiences reported by some of my participants as will now be discussed.

Sexuality

The sexualized meaning of the breasts seemed to produce the most complex emotions in my participants. For those who felt that their breast was important to the way they felt about themselves in terms of sexual attractiveness and desirability, loss of the breast was felt as an assault on their sexuality. The widely accepted cultural view of sexuality becoming less important as women get older is complicated by the women in their late 50s and early 60s in my sample who spoke about the effect on their sexuality as a major factor in their experience. For example 61 year-old Barbara D who had lost her hair through chemotherapy then had a mastectomy but no reconstruction, told me about her body image:

My hair, although it came back it's not very thick and that's down to the tablets apparently. Skin is very very sensitive. Whether I eat or whether I exercise, my weight is solid, it won't shift.

Consequently, it seemed to have affected Barbara's view of herself as sexually attractive:

It's changed **me**. It changes how I feel sexually because I mean it's quite a big part and yes that changed. Because I don't, I don't feel attractive any more. And

that I find upsetting. What with my hair and that as well [participant's emphasis].

Barbara is reporting how her sexuality was an important part of her identity and that she is distressed at having to adjust to a new sexual self in the wake of disruption to sexualized parts of her appearance. It seems that because her hair looked different to how it had done before she lost it, the additional loss of her breast was felt to be too much of an assault on the way Barbara saw herself. Barbara's comment 'it's quite a big part' suggests that her breast was a big part of feeling sexually attractive. This is similar to the second group of women in Fallbjork et al's (2012) study who described losing their breast as losing part of their self. For them, as for Barbara, the breast was not a 'sexually neutral' part of the body.

It seems that when the breast was perceived as a crucial aspect of womanhood and/or sexuality, it presented more problems, even for the older participants. According to Langellier & Sullivan (1998), the sexualized meaning of the breast incorporates not only the outward appearance but also the mental and emotional aspects of the breasted experience. This view of the breast as sexualized is therefore most pertinent to the way that women feel about themselves as well as the effects on intimate relationships. Some participants such as 51 year-old Connie, commented on how their sexual relationships had altered since their mastectomy:

Being really personal, behind the bedroom door, don't let **anyone** tell you that it doesn't alter things because it does. Absolutely does.

D in what way?

C in the way you feel. I don't know, Jim's not the type of person that would um tell you the truth [laughs] And I've actually heard stories erm there was one lady in the ward with me and they'd been married 28 years and her husband just couldn't hack it and their marriage came to an end..this is common. Honestly, this really is. It shouldn't matter but to a woman if a partner had had I dunno testicle cancer or whatever the woman would just be okay whatever. But men don't handle it the same, they really don't.

It is noticeable that when I asked how her changed body had 'altered things', Connie told me that it had altered the way **she** felt, which indicates the mental and emotional aspects of sexuality. She also revealed that she worries that it will change the way other people (particularly her husband) feel about her. It seems that Connie no longer feels secure because surgery had disrupted her understanding of herself and her marriage, echoing Wilmoth's (2001) argument that sexuality is largely dependent on self-confidence. Wilmoth (2001), who interviewed 18 women who were between 3 months and 10 years post-treatment for breast cancer, found that confidence was a major aspect of their sexual self. It was more important to their feelings regarding their sexuality than the mechanics of lovemaking which were affected by menopausal symptoms. Wilmoth argues that self-esteem and body image seemed to be more important to her participants than the side effects of treatments on sexual functioning. This contrasts with the majority of the research into sexuality after breast cancer which uses quantitative methods to measure frequency of sexual intercourse which Wilmoth argues is based on male ideas of sexual satisfaction. Connie perhaps fears

that her marriage may suffer in the same way as the stories she had heard about other people, although in those cases she blamed men who 'don't handle it the same'. Connie's comments also suggest that male sexuality is seen as more active, whereas female sexuality is passive and receiving. It seems that adaptation to living with the sexual consequences of breast cancer is strongly influenced by the type of support women receive from their partner, as Wilmoth (2001) suggests. Participants in the current study who reported that their partner had accepted the breast loss seemed to find it easier to adjust themselves. For example Nina told me that her partner had said:

'Your mouth's still the same ..you still answer back so nothing's changed much'. But no it doesn't bother him one little bit. And I said to him 'do you think I ought to have a mastec-?' he says 'well don't have one on everybody else's account, you have one if you want it doing' he says 'cus I just don't see anything else but **you**' you know he says 'tell you the truth, I don't even notice' I says 'really?' he says 'it doesn't even enter my head' you know. No it doesn't bother him one little bit.

Nina was very talkative in her interview, which her partner seems to be referring to with his comment 'your mouth's still the same'. From the way that Nina told me this story it seems that as long as that aspect of her remained constant then she was still the same as far as he was concerned. However, this does not seem to be a common perception as Nina found out when she returned to work after her mastectomy and reported this conversation with a colleague:

She said to me, 'it must be awful just having one breast' and I said 'no, not really' I said, 'it's worse knowing you've got cancer, but it's not bad knowing you've got one breast. That's how I see it.' And she said 'oh I don't think he would touch me' and I went 'would you touch him if he lost an arm or a leg?' and she went 'yeah'. I said 'well that means that he can't love you enough.'

This anecdote highlights the sexualised understanding of breasts as opposed to other body parts. Nina seems to be rejecting the necessity for women to have two breasts in order to maintain a loving relationship and minimizing the 'special' status afforded to breasts in heterosexual relationships. Nina's reported experience also reveals the way that intimate details are commented on publicly, as some of the other participants reported and which is particularly well illustrated by Joy's experience. Joy had a mastectomy (which she referred to as a mass-ectomy, explaining her reasoning that it was the whole (mass) of the breast that was removed rather than a lump, as in lumpectomy). Joy told me she was happy with her decision and so was her husband, but she reported the following conversations with her husband's cousin. This was a theme that Joy returned to often in the narrative, including after the interview had ended, seemingly unaware that she had told me the same thing before. As discussed in the previous two chapters, repetition seems to indicate that this aspect of the experience was one that Joy was struggling to come to terms with. Its repetition was one of the main things that struck me during the interview. Joy reported how the intrusive nature of the question had shocked her:

1. And a lot of people, I mean people did say to me, 'what does your husband think about you having a mass-

ectomy?' and I was shocked, shocked! That they would ask. I mean one of `em was his cousin. I mean she's [pause] I was shocked. 'What's our Ben think about it?' Just like that. And I says, I didn't know how to answer it for a start and then I said 'what's it got to do with him? it's my body' I says 'but he has said he'll go with whatever I say'. (lines 190-196)

2. So she said 'what does our Ben think to that?' and I was a bit shocked that she actually asked me. And I says 'well he's just accepted that that's my decision'. I mean he's never actually said to me, well he has since, you've made the right decision, but he never once influenced it all the while. It was my decision and he said 'I'll go with anything you say'. And it was my decision and a lot of people said to me 'you want to have a mass-ectomy cus it's done with then.' (604-610)
3. She rung up and she was talking to me and wishing me well and she says 'what are you having done?' and I said 'I'm going to have the mass-ectomy' and she said 'ooh, you've made your mind up then?' And I said 'yeah' and she says 'what does our Ben think to that?' and I, I was a bit gobsmacked really to put it bluntly, I didn't know what to say to her. And I just said 'well he, he's with whatever decision I make' I said. 'He'd much rather have me than nothing', do you know what I mean? To be quite honest with you I looked at it as a sex thing. I did. (618-624)

Analysis of the three excerpts uncovers issues pertaining to control over the body and of personal information. It seems

that Joy was shocked at having to justify her decision to have a mastectomy to other people. She felt that it was a private matter yet other people seemed to feel able to question it. At these points in her narrative, Joy seemed to be expressing a view of her breast in a medicalized way (Langellier & Sullivan 1998), i.e. as a diseased body part that needed to be cut off. She is suggesting that what was most important to her husband was that she was alive because she claimed he would 'rather have me than nothing.' For Joy, the shocking part of the exchange seems to be that the cousin was portraying the breast in a sexual way which Joy seems to have found inappropriate, as well as being an intrusion into her privacy.

The cousin's question regarding the impact on her husband of the mastectomy (and according to Joy's suspicions, her sex life) provide evidence of the perception of women's bodies and sexuality not only as the property of men, but also of wider society; hence Joy's comment 'a lot of people said to me you want to have a mass-ectomy (sic)'. It is therefore significant that Joy asserts 'it's my body' and twice says that the mastectomy was 'my decision'. It reveals how women continue to struggle over bodies that are perceived to belong to everyone except themselves indicating, as Young (1990:192) argues, that 'a phallogocentric culture tends not to think of a woman's breasts as hers..her body belongs to others, her husband, her lover, her baby.'

The assumption both of male 'ownership' of the body and of heterosexuality was highlighted in my interview with Andrea, a 63 year-old lesbian who reported that she had volunteered to be a trainer for the Breast Cancer Care charity. She told me that she had pointed out to the other volunteer helpers that a commonly asked question put to women undergoing

mastectomy is: 'and how does your husband feel?' Andrea reported that she felt that assumptions were being made about a woman's sexuality:

A woman of a certain age, they might **these** days, this was ten years ago, these days they might say partner, but they assume. So, you know, there were these women going 'never thought of that!'

This echoes Young's (1990) argument that there is a heterosexist assumption that the major cause of emotional upset for a woman who has had breast surgery is worry about how it might affect their husband or male lover. Wilkinson & Kitzinger (1993) quote a surgeon who apparently told a patient that he would want his wife to have reconstruction which they suggest is an indication of the importance placed on male partners' preferences. This was only mentioned by one of my participants, 43 year-old Karen, who was on the waiting list for reconstruction when I interviewed her. Karen voiced her concerns about her husband's reaction to her reconstructed breast:

But the other part, you know, it's 'what will my husband-?' it's about how they see it because my husband's a bit of a, he's quite a boob man so I suppose he's going to mourn the loss of it more than I am really erm. Is it a boob to you? Do you know what I mean? Cus it is about shape predominantly for me, I do worry about how husband sees it really that's the thing because it's still, you know, is it your breast or is it not your breast because it's a reconstruction.

Karen's comments suggest that she fears that her reconstructed breast will feel alien to her and no longer intrinsic to her sense of self. Although she reports that what is most important to her is that it will restore her body shape, she is displaying signs of insecurity by wondering whether her husband will still find her sexually desirable. Her question 'is it a boob to you?' highlights the difference between the reconstruction looking like a natural breast, and feeling like one. I will return to this point in due course.

Nina, however, told me how she felt that other people should not influence the decision:

I think if somebody is going to be [pause] if a partner is going to say I had to have a reconstruction, **that** would then just say to me 'go away, just go away' cus I don't need it, you know. Not only have you got the pressure of having cancer and having your breast off but then you've got the pressure of having to be normal because the other person wants you to. And I just think they have to want you for you, do you know what I'm saying? They've got to want you for you cus that then comes after doesn't it?

Interestingly, Nina used the phrase 'the pressure of having to be normal' even though she had previously said that having only one breast did not make her 'a freak'. It is indicative that she is aware of societal pressure put on women to look a certain way, specifically two-breasted, and how losing a breast is considered 'abnormal'. Similar findings were reported by Rubin et al (2009) who interviewed 48 women about their motivations for breast surgery, 20 of whom were breast cancer patients whose breast(s) were being reconstructed.

They found that the predominant reason reported by women for having surgery was to 'look normal' but whereas the breast cancer patients reported that they wanted to be restored to how they looked before, the other participants reported that they wanted to stop looking different to other women. Hence, normal seems to hold different meanings to different people, as will be discussed in the following section.

The quest for normality

We have seen in the first part of the chapter how the meanings that women ascribe to their breasts influenced their feelings regarding their loss. In the UK at the present time the NHS guidelines say that all women with early-stage breast cancer should be offered reconstructive surgery. This is a quote from the National Institute for Health and Clinical Excellence (NICE) guidelines which recommend that medical professionals:

Discuss immediate breast reconstruction with all patients who are being advised to have a mastectomy, and offer it except where significant comorbidity or (the need for) adjuvant therapy may preclude this option. All appropriate breast reconstruction options should be offered and discussed with patients, irrespective of whether they are all available locally. (NICE clinical guideline 80, 2009:10)

This suggests that there is an assumption that all women would want to consider reconstructive surgery. However, for numerous reasons, some of which I have already mentioned, many of my participants chose not to do so. In the following

section I discuss the options available to my participants and their comments about their experiences surrounding this issue. I will also discuss problems that participants experienced with reconstructed breasts including a lack of sensation and an unnatural feel. Laced throughout this subject is the implication of the necessity to cover up the missing breast(s) and this is presented as being in the woman's interest, as illustrated by Nina's reported experience immediately after her mastectomy:

When you're in hospital they put you this false one on more or less the next day with a spongy thing inside which I think is absolutely revolting..I said 'I'm not wearing it'. Then they tried again a bit later in the afternoon.. this woman came round, I think she was a physiotherapist ..and she said 'just try it on it might make you feel better'. To what? Feel better to what? I can see that it's not there. I said 'I don't have a problem with it not being there, the only thing in my head is that it's off and it's gone', you know. And she said 'well you probably need to get back to normal'. And there was a lady with one leg; she'd been in there several weeks. I said 'have you told that lady there that she has to go out with a leg otherwise she won't feel normal?' And she just went 'alright that's fine then'.

Nina's experience highlights how the concept of 'normal' is concerned with the presentation of a culturally acceptable body. Again, there is the comparison being made between the loss of her breast to the other patient's loss of her leg. Yet Nina's insistence that there should be no difference only served to reinforce the cultural significance of the breast when compared to body parts that were not imbued with sexual symbolism. A similar observation was made by Rosenbaum &

Roos (2000:155) who interviewed 40 women who were between 6 weeks and 5 years post treatment for breast cancer. They argue that women are encouraged to disguise missing breasts because of the stigma attached to not only having a potentially fatal disease but of losing a 'value-laden body part'.

The term 'normal' cropped up constantly in my participants' narratives. For example in Sam's narrative she used it when describing life, behaviour, appearance and relationships. Yet for such a widely used concept there seems to have been little research into what is meant by normal, particularly in relation to women's bodies that have been disrupted by breast surgery. An exception is an interview study carried out in America by Denford et al (2011). 35 women who had been referred for plastic surgery following mastectomy were asked about their experiences or expectations of reconstruction, depending on whether they were interviewed before or after surgery. The purpose of the study was to understand women's motivations for having reconstructive surgery in order for clinicians to manage their expectations more effectively. Normality was a common theme within the interviews of both sets of patients and Denford et al (2011) identified four meanings:

- i. Appearance (looking normal). This included sub themes of looking normal to others, looking as they did before surgery and looking natural
- ii. Behaviour (being able to carry out activities as normal)
- iii. Reconstructing normality (adapting to a 'new normal')
- iv. Normal health (absence of illness).

Denford et al (2011:557) found 'tentative links' between women's treatment choices and their definition of normal. For

example when it was important to them to 'look normal' they tended to opt for the more natural looking implant, whereas those whose aim was normal health went for what they considered to be the safest option. Thus, though reconstructive surgery is associated with a quest for normalcy, it is worth considering individual perceptions of what normal means as this affects their satisfaction or otherwise with reconstructive surgery.

In a separate study, Kendrick (2008) discusses normality in respect of the literature used to promote a programme of make-up and beauty advice for breast cancer patients. She argues that although such schemes are grounded in good intentions, the way that women are encouraged to disguise the effects of cancer treatments can unwittingly reinforce the idea that stigma is located in the individual rather than in society. Similar projects exist in the UK which I have seen advertised in the breast clinic (<http://www.lookgoodfeelbetter.co.uk/site/index.cfm> accessed 15/2/11). Kendrick argues that despite the many women who are undergoing treatment for breast cancer at any one time, the true extent of the number of people affected is kept hidden from public view as a result of 'a concerted social effort' to make them unidentifiable (Kendrick 2008:267). The consequences of this push for normalization will be discussed in the following chapter, but for now I will consider the concept of being 'normal' in relation to breast reconstruction.

Earlier in this chapter I discussed Langellier & Sullivan's (1998) study of women's perceptions of their breast following treatment for breast cancer in America. A major difference between their study and mine is that 8 out of the 10 women in

their sample who had a mastectomy declined reconstructive surgery. The reasons they gave were that they were unwilling to travel to a different part of the state where the operations were available, and that they were reluctant to discuss reconstruction with a man. At the time there were no female surgeons doing these operations at the hospitals where their participants were treated. This contrasts with my participants who all had the option of breast reconstruction, as set out in the NICE guidelines quoted earlier. The position regarding reconstruction for women in the UK at the time of writing is illustrated by the following experience. It happened on one of the occasions that I visited the breast cancer support group at the hospital where I was treated:

There was a talk about breast reconstruction which was coincidentally given by my consultant. It was interesting because she had more time to fully explain the procedures than in a consultation plus she was not talking about me so I did not have that stress. She said that when we got our results the consultant would have had a meeting with 8-10 people about the mammogram/biopsy results and they would have discussed the best course of treatment. The consultant explained the different types of operation available (from stomach, back or implants) and said that their aim is to help improve women's quality of life by helping them feel confident when dressed; although she admitted that a reconstructed breast would never look like a real one. During the Q &A session, a man (the only man in the room) asked a question. There was an audible gasp at hearing a man's voice. His wife was having chemotherapy and he wanted to know when she

would be offered reconstruction. The consultant said his wife needed to have her life-saving treatment first but not to worry. (Breast cancer support group meeting 15/3/11).

I think I was not alone in finding this talk very reassuring. It suggested that the hours we had spent waiting for the consultant to arrive in the clinic were due to her spending time discussing the best option for each woman. It also implied that they considered that we had sufficient life left to merit having complicated and expensive surgery aimed at improving the quality of that life.

Although the support group is allegedly for anyone affected by breast cancer, in practice it tends to be just women who have actually had it who attend, although sometimes they take a (female) friend or relative. I visited the support group on three occasions and this was the only time that a man was present. It was a very female domain where intimate matters were discussed candidly, and often humorously. This may explain the 'audible gasp' at hearing a male voice. The surgeon's response was an interesting mix of reassurance and a gentle suggestion that the couple should direct their energy primarily toward finishing the chemotherapy because reconstruction could be done later. It served as a reminder that appearance, although important, was less so than life-saving treatment.

In brief, the types of reconstructive surgery offered to my participants were as follows:

- i. Silicone implant – an implant is inserted underneath the chest muscle. This is not suitable for women who have a large and/or droopy remaining breast since the implant

results in a solid and rounded appearance which may look incongruous.

- ii. Tissue expansion – an inflatable implant is put under the chest muscle and gradually expanded over the following weeks with injections of saline solution. It is a lengthier process than using silicone, plus it is unsuitable for women with large breasts as it is difficult to achieve a good match.
- iii. Transverse rectus abdominus muscle (TRAM) flap – this uses part of a muscle which runs from the breastbone to the pubic bone as well as skin and fat. Problems with this include weakened abdominal muscles and increased possibility of a hernia.
- iv. Deep inferior epigastric perforator (DIEP) flap – this just uses skin and fat from the abdomen along with the blood vessel needed to keep it alive. DIEP refers to the blood vessel used in the reconstruction. Although it does not weaken the muscles, there is a higher risk of failure than the TRAM procedure or the reconstruction using a muscle from the back described below.
- v. Latissimus dorsi flap – uses a muscle which is located under the shoulder blade. Without disturbing the blood supply, the muscle is pulled forward and shaped to form a new breast. Sometimes a silicone implant is used if it is necessary to augment the breast.

(Adapted from information supplied by Cancer Research UK (2012) and Breast Cancer Care (2006))

There are other reconstructions available using skin and fat from the buttocks or thighs, but none of these were offered to

my participants. Also not all of the above options were available to all participants as it depended on the expertise of surgeons at the hospital in which they were treated. Consequently, only a few participants were offered the latissimus dorsi flap. Fentiman & Farhadi (2012), a breast surgeon and plastic surgeon respectively based at a leading cancer hospital in the UK, highlight the discrepancy between the NICE guidelines outlined earlier in the chapter which state that 'all appropriate breast reconstruction options should be offered and discussed with patients, irrespective of whether they are all available locally,' and what happens in practice, which appears to be confirmed by my participants' experiences.

The surgery is sometimes done at the same time as the mastectomy but in circumstances where this is not possible it can be done months or even years later. In the case of my participants, of the 19 who had the whole of one or both breasts removed, only 7 had immediate reconstruction. Jean and Viv had the silicone implant, Phoebe had the tissue expansion, Malaika and Gabrielle had the DIEP and Kate and Sophie had the same operation as me which was the latissimus dorsi flap. 3 others (Sam, Nina and Karen) were waiting for reconstruction, leaving almost half the sample who for various reasons had decided against having the operation. Fallbjork et al (2012) observe that there is very little research which explores the reasons why women decline the offer of reconstruction after mastectomy. In both Fallbjork's study and the current study, as discussed previously, some women's reasons centred on their perception of the importance of their breast(s) to their sexuality and sometimes their age was a contributory factor. Other reasons included a reluctance to

undergo further extensive surgery or a perception that a reconstructed breast would feel unnatural, as will be discussed in due course.

Expectations

Most of the participants in the current study were interviewed at a point where they had either had reconstructive surgery or made the decision not to do so. However two of the participants (Nina and Sam), who each had a mastectomy, spoke at length about the topic of reconstruction which revealed that both women seemed to have certain expectations regarding reconstructive surgery. Sam seemed to have pinned her future hopes on the operation and felt unable to progress until she had it:

There's so many things I can't do because I've got this hanging over me. I just want to get on, get the operation done and get on with my life.

As previously described in chapter 5, a series of incidents had meant that 43 year-old single parent Sam perceived herself to be in a period of limbo when I met her. Deeply unsatisfied with her job, Sam reported that she felt unable to find another one as she knew she would have to take sick leave when she had surgery. For Sam, the problems with her altered body seemed to have become a preoccupation and she vocalized her frustration at the delay with the surgery which she perceived as preventing her from forming a new relationship:

When you're going through all of the treatment and all of the stuff obviously all you keep thinking is 'this is going to keep me alive', there's a purpose to it right?

And then obviously you get through that and it gets you a while to get back to normal. You know, you get back to work, try and get your life back. But now its hit me that (pause) I'm only young, I've got one breast, and I feel like I'm on the scrapheap. And I'm trying to help myself and nobody's listening to me. And that's really upsetting. This is actually one of the most difficult parts emotionally. Because I can't go on for the rest of my life like this. I don't want to be on my own forever. You know, I've been through enough and this is really difficult.

This indicates that Sam seems to be suffering post-traumatic symptoms with her comment 'now it's hit me'. This is similar to the findings of Fallbjork et al (2012) who reported that for all of their participants the priority was to have their breast removed in order to survive but for some of them, and also for Sam, the subsequent passage of time had revealed the profound impact of the mastectomy on their identity. Fallbjork et al (2012:45) argue that 'for these women, breast reconstruction was unavoidable: it was a necessity of being restored as a person. It gave hope of regaining the self as a person and a woman'. Even though she reported that she had been able to resume some semblance of normal behaviour by returning to work, Sam seemed to still be experiencing physical and social disruption. Denford et al (2011) argue that for some women, reconstruction was the final step of a process of resumption of some sort of normality which Sam seemed to be missing out on. Later, Sam explained her reticence towards meeting someone despite her apparent loneliness:

So I'm spending more and more time on my own and I need somebody in my life, to share things with. And I can't [pause] there's no way that I can put myself in a situation where I would have to explain to somebody that I've only got one [pause] breast. Because I wouldn't want to face that rejection and I wouldn't want to repulse somebody.

As was discussed in the previous chapter, Sam presents events in this way which locates agency- and responsibility - elsewhere but it is interesting to note how in the context of Sam's single-status, her major concern seems to be to conform with the norms of society. Bordo (2003:20) argues that this does not mean that women like Sam are passive recipients of ideal body images that are fed to us through the media, but that we are aware as women that in order to be sexually desirable we must conform to norms of appearance which 'shape the desires and perceptions of potential lovers'. Goffman (1963) suggests that stigma management is on a continuum from public life to intimacy. Although Sam would be able to conceal her missing breast when clothed, it would be a different matter to be seen naked by a potential partner. Sam seems to think that her appearance would lead to automatic rejection and was anticipating that she would be stigmatized because of her missing breast. Scambler (2008) describes two types of stigma, enacted and felt. Enacted stigma is where people actually experience discrimination as will be discussed in the following chapter, whereas Sam seems to be expressing felt stigma which are feelings of shame, or fear of discrimination due to cultural unacceptability. This was not Sam's only concern. She went on to tell me:

I mean really deep down inside I think that if somebody loves you, gets to care about who you are, then it shouldn't matter. But I also know what men are like...I don't want anybody thinking, 'god it was a mistake taking her on' because it's so visual isn't it? It's always gonna be a reminder to them that you've had cancer as well. So they could think 'is she gonna be here? Is there any point in having this relationship with her?' Whereas..at least if you look relatively normal it's not gonna be such a [pause] smack in the face reminder is it?

Sam raised a point that hitherto had not been raised, that the sight of her body would also reinforce a partner's fears that she may die of cancer. Sam seems to be very defensive, fearing rejection not only because of her 'inadequate' body, but that she may prove to be a liability because she may become ill and die. A partner may regret 'taking her on' when there was 'no point' if there was no future in the relationship. It suggests the ongoing fear of recurrence and consequent lack of a perceived future, which was discussed in chapter 5. Sam is suggesting that a reconstruction would make her look 'relatively normal' thus protecting a potential partner from receiving such a reminder every time he saw her body.

For Nina however, having reconstructive surgery seemed to be intrinsically connected to restoring her sense of self. As was discussed in the previous two chapters, Nina felt that she had changed fundamentally as a result of the traumas she had been through, particularly the time when she was arrested and held in a police cell. Nina reported that despite her acceptance of her appearance, she was considering having the surgery because her daughter seemed to believe that

reconstruction would help her to come to terms with the trauma that had affected her personality:

I think she thinks that if I have it done, I'll go back to how I used to be.

D what do you mean?

F because she thinks I've changed. I don't think she realises it's probably the arrest that's changed me rather than [the mastectomy].

This is particularly interesting because Nina seems to be contradicting herself as throughout her narrative she had been adamant that there should be no distinction between losing a breast and losing a leg. Additionally she had said that the decision should not be based on anyone else's opinion, as discussed earlier in this chapter. Nonetheless, having surgery seemed to be part of Nina's plan to reconstruct normality for the sake of her family who believed that once her body shape was restored, she would become her 'old self' once again. This echoes the view of some of the participants in Denford et al's (2011) study who believed that reconstructing their lost breast could help restore their sense of identity. However, Nina told me at the end of the interview that she was reconsidering her decision:

Do you know what? Talking to you it makes me even **less** bothered about having reconstruction because it's not the end of the world is it? It's not. I probably will have it done for me. I probably will have it done but you know if I don't, it's not a big deal either erm [pause] because I'm still me. [participant's emphasis]

Nina seemed to work through contradictory feelings towards her missing breast in the process of forming her narrative. Although she seemed to realize that surgery would not make a difference to her personality saying 'I'm still me', she also said she probably would have it done 'for me'⁸. According to Rubin et al (2009:667) this can be a way of taking back control as they argue that 'after surviving cancer or living with long-standing feelings of shame or inadequacy, taking action can indeed feel empowering'. However, action can also mean deciding not to have surgery in a climate where it is the expected course of action. As mentioned before, Connie felt that her mastectomy had altered things 'behind the bedroom door'. Rubin et al (2009) argue that a lack of confidence in the appearance of the breast can interfere with sexual functioning and therefore some women sought surgery in order to make them appear more socially acceptable. However, Connie reported that she had decided not to seek reconstructive surgery and talked about her husband's feelings in the treatment decision making process:

They'd offered me what they term as their 5 star reconstruction ..and showed us photographs and everything else and um the plastics guy came in and talked to me about it, the breast nurse came in and ..it just wasn't for me. And they said to Jim, 'can you give an honest opinion of these photographs, how you feel?'
'And he says [laughs] 'Frankenstein's laboratory'! I don't

⁸ When I spoke to Nina 18 months after her interview, she told me that she was on the waiting list to have reconstructive surgery using the DIEP procedure. She said that she was fed up with the discomfort of wearing a prosthesis, particularly during the hot summer months when she would prefer not to wear a bra. She seems to be echoing the views of the third group in Fallbjork et al's (2012) study for whom breast loss had not impacted on their sense of womanhood, but reconstruction was welcomed as a way of restoring some 'normality.' This echoes my own motivation for having reconstructive surgery, which was to minimise the disruption resulting from mastectomy.

think they were very pleased but - I'm sure it is okay, but for other people.

It seems that Connie had resisted pressure from medical staff to have surgery despite the hard sell tactic of offering her the '5 star reconstruction', although she did not elaborate on what this might entail. Kasper (1994), who interviewed 29 women about their breast cancer experiences, argues that the refusal of one of her participants to have reconstruction 'flies in the face of social expectation that every woman who lost a breast would want it replaced' (Kasper, 1994:277). It also suggests that reconstruction has become an increasingly normalized practice, as the NICE guidelines outlined earlier seem to confirm. Consequently, failure to comply, and even criticizing the results of surgery as Connie's husband apparently did, seemed to have been an unexpected reaction.

At the time of writing, this was amidst the context of controversy over PIP breast implants⁹ which has revealed mixed attitudes towards breast surgery. On the one hand it is expected that women who lose a breast as a result of cancer should want to have surgery, as Connie's experience demonstrates. On the other hand, women without cancer are criticized when they choose to have surgery for cosmetic reasons, regardless of their reasons for doing so, which may have included psychological distress at their perceived 'abnormality'. Rowsell et al (2000) interviewed 23 women who had breast implants, half of whom had been treated for breast cancer. They found that despite the negative stereotypes of women undergoing breast enhancing surgery for purely

⁹ This refers to implants made by a French firm, Poly Implant Prothese, which were found to have contained industrial silicone and subsequently banned. Women who had them fitted on the NHS were allowed to have them replaced free of charge. However, women who had paid to have implants and the private health provider had gone out of business could only have them replaced by the NHS if they ruptured.

cosmetic reasons, the motives of both groups of women were similar in that they just wanted to normalize their appearance. They were not looking to be different or better than other women despite the way they were portrayed in the media. However, although their motivations were similar, the experiences reported by the two groups of women were very different. Having implants was assumed to be part of the healing process for the women who had a mastectomy due to breast cancer and required no further justification. However, the women who opted for implants for cosmetic reasons seemed conscious of potential judgments and felt the need to justify their decision as being influenced by psychological distress rather than vanity. In the case of the PiP scandal, the lack of compassion for such women was indicated by unwillingness to allow women who had paid privately to have potentially dangerous implants to have them removed in NHS hospitals. For example, one woman claimed she had been referred to by medical professionals as a 'waste of resources' (BBC *Newsnight* 7/2/12). This suggests that there may be an unwritten perception of good and bad reasons for surgery which are highlighted when contrasting these two groups of women, one group who are encouraged to have surgery and another that are vilified for the same decision. However, a rare study of women undergoing breast reduction surgery (Naugler, 2009) highlights the tenuous nature of this divide because even though it is not life-saving surgery, breast reduction is still perceived to be related to health issues such as back or shoulder problems. Furthermore, Naugler argues that the resultant scarring balances the scales of fairness because breast reduction is not perceived to be pure gain for the women. There are equal measures of suffering and enhancement, therefore the procedure is not considered

cosmetic. Clearly, breast surgery is a complex issue that merits further investigation.

The experience of reconstructed breasts

As mentioned previously Connie had declined reconstructive surgery. Her decision may be based on her husband's negative reaction to the photographs of women post-surgery, or alternatively she may have felt supported by him in her decision not to comply. If it was the latter, her decision may have been based on her opinion of a friend's reconstruction that she told me about:

Just looking at [her] chest, to me it looks like half a tennis ball stuck on. Because there's nothing in your body that's the same consistency or whatever as breast tissue.

Connie seems to be describing an apparent side-effect of implants known as 'capsular contracture' where tough fibrous tissue forms around the implant. According to Sweeney (2009) who had breast augmentation using implants and suffered the same fate, this is a common problem. Sweeney reports that the ensuing rounded appearance made her breasts easily recognizable as 'fake' and outed her as a recipient of breast implants. It seems that Connie, with her stated focus on keeping her breast cancer secret, did not want to risk the same thing happening to her. In the current study, Jean told me about her similar experience:

It was like a cricket ball and it used to go dead hard. I've had these dead handsome doctors laying on my

chest squeezing it because a membrane grows over it and if you can crack the membrane it'll go softer.

In a parody of a sensual act of squeezing her breast, Jean described how 'dead handsome doctors lay on [her] chest' but rather than being a tender act of lovemaking it was a harsh procedure designed to 'crack the membrane'. According to Sweeney (2009:243) this practice is 'a dangerous – some say negligent – procedure because of the risk of damage to the implant membrane' which she managed to avoid by opting to have her implants removed.

Another participant, Sophie, reported that she was very pleased with the results of her reconstructive surgery because she 'looked completely normal'. However, she told me that she experienced some side-effects as a consequence of her surgery which had involved using muscle from her back to reconstruct the breast:

Because I've still got the muscle attached, it sounds awful, but I can actually tweak this side! [laughs] which is quite funny. So I can actually tweak the muscle which is quite alarming. And the other thing that was a real problem for me was getting cold. And I still have this slight problem even now because when you're cold your muscles contract and of course this is holding in an implant, if I get cold the muscle still, whereas normally it doesn't this will constrict like that and I go [sharp intake of breath]. And the first couple of years it used to cause me real problems I had to make sure I was warm because it was really painful. But other than that..I'm playing badminton and golf and swimming and all those things now. And the movement in that shoulder is

different to the movement in that shoulder but it's amazing how your body compensates. Yeah it's fantastic.

Sophie reported that the benefits of looking normal and being able to play sport compensated for the few problems she reported having. It seems that Sophie was able to 'reconstruct normality', as Denford et al (2011) propose. Although she was not the same as she had been prior to her operation, with a few adjustments she had been able to resume her normal activities. However, Kate who had the same type of surgery described disturbing side-effects:

I get pain from it all the time. I get a very like cramp? It's like a muscular pain for no apparent reason at all.

D in your back?

K Here (indicates under her arm) and the oncologist told me that muscle has memory. And that sometimes what you're doing is perfectly reasonable but that muscle was in your back and that is not perfectly reasonable because it's still in your back, they don't chop it out they pull it forward. They slice it and pull it through...so I have a lot of problems with that ..if I sort of move the wrong way or that sort of thing.

When I asked her, Kate told me that nobody had warned her of the side-effects and claimed that it was:

The worst thing I have ever had done in my life! I would never have that done again and I would never tell anyone else to have it done either.

It seems that surgeons may have prioritized the benefits of this type of surgery over the risks. Similarly, the literature provided by cancer charities regarding the latissimus dorsi flap

only warns of the 15cm scar on the back, although they suggest this will be in a position where 'you can hide it under your bra' (cancerhelp.cancerresearchuk.org accessed 8/5/12). However, Fentiman & Farhadi (2012), commenting on the availability of reconstructive surgery, say that a drawback of this surgery is shoulder dysfunction. This was the operation that I had and the only side-effects I was warned about were that it would limit my ability to do rock-climbing or horse-riding. As I had never done either of those activities, and did not intend to do so, I happily went ahead with the operation. Although I do not suffer the same side-effects as Kate reported, I suffer weakness and discomfort in my shoulder. There is no sensation in my reconstructed breast, it does not move 'in a fluid and changing' way as an unbound breast ought to do (Young 1990:195), and when I exercise it flexes like a muscle in the way that Kate describes. Rowsell et al (2000) found similar evidence of the downsides of implants being downplayed in contrast to the benefits. One of their participants reported being told that if she 'popped these in' she would 'look like a woman [and] feel like a woman and it will be for life' (Rowsell et al, 2000:211)¹⁰.

Another participant, Viv, had reconstructive surgery which was meant to not only restore but enhance her previous body shape. However she reported that she was disappointed with the results:

¹⁰ Although this apparently happened in 1990, Sweeney (2009) said that she was given a similar impression that she would have the same implants for the rest of her life when she had her operation. She reports that a friend who had an operation in 2000 had also not been warned of the limited lifespan of the implant, even though it is common practice in other operations involving artificial body parts such as hip replacements.

I had the silicone reconstruction. But what was really nice, cus it was a female doctor, she says if you want we can make your boobs bigger than what they was before. So I've got a silicone implant, a little one on that side, and that's full silicone. So that was alright! [laughs] yeah I look better than before! I don't really but I pretend I do.

Viv seems to have realized that though the surgery had apparently been successful in terms of her appearance to other people to whom she could 'pretend' it was 'better than before', the way she experienced the implants in her body meant that she was unconvinced. As Goffman (1959) points out:

'The performer may not be taken in at all by his own routine. This possibility is understandable since no one is in quite as good an observational position to see through the act as the person who puts it on.' (Goffman, 1959:28)

It seems that Viv's experience is evidence of Denford et al's (2011) argument that some women have high expectations of reconstructive surgery, anticipating that their new body will not only restore them to their previous standards but that they will be able to conform with societal perceptions of normality. Viv continued:

You look alright clothed but not undressed you don't. It's awful [long pause] like my husband tries to be nice about it but you know you look (pause) like a freak.

D so do you think that affects how you feel, the er, the way you look

V yeah. (pause) yeah. Yeah definitely.

This quote once again reveals the way that the breast can be intrinsically related to feelings of sexual desirability and confidence. Despite her husband's apparent attempts to reassure her, Viv's reported experience indicates that her sexuality has been profoundly affected by the disruption to her body. Viv's comments suggest that she is disappointed by the appearance of her breasts, perhaps because the surgeon had oversold the benefits of surgery to increase the size of both breasts. It seems that she had not been warned that they would never resemble natural breasts when naked, although this was emphasized by the consultant at the support group meeting described earlier. Viv's apparent disappointment may have been compounded because of the lack of sensation in the reconstructed breasts, which can be problematic. She told me:

It's just a lump of silicone. And it's really hard and [pause] it's not nice.

This problem was also highlighted by Hallowell (2000) whose participants described their reconstructed breasts as feeling unnatural, using terms such as 'solid' and 'like blocks'. Hallowell therefore argues that although reconstruction can help women to look natural, a feminine identity is not just about looking a certain way but involves the way the body feels to themselves and to others. Young (1990) argues that feeling is the most important part of the breasted experience for women but that this aspect tends to be sidelined, with looks being given precedence. As a result, many women end up with breasts that feel unnatural and although they may look aesthetically pleasing, they have lost sexual feelings for

the women. This suggests that breasts are mainly seen as objects for men's pleasure at the expense of women's.

The lack of sensation was also commented on by Wendy who told me that prior to being diagnosed with DCIS she had very big breasts. As her tumour was apparently 'the size of an orange' she reported that she had to have a partial mastectomy and a breast reduction on the other breast to make them equal. She told me:

When they were looking, telling me how symmetrical they were and how great they were you know, they are painful they're not comfortable. I feel like when you're pre-menstrual, they're very tender, and I haven't got sensation in the nipple. .. I don't allow it to be a big deal but it could be quite a big deal.

Even though Wendy reported that she was happy with the surgery to remove the lump and reduce the other breast to match, she told me that she resented the assumption that she should prefer 'small pert breasts' to her imperfect large ones:

My one thought, all the way along was [pause] there was a lot of people looking at me saying 'ooh that's a good job' and inwardly I was thinking 'actually I quite liked my big, voluptuous breasts you know they're not everybody's cup of tea and I've got pert little ones now but I wanted the ones I had before' and nobody ever acknowledged that, that I might have actually been happy with droopy breasts, down to my kneecaps!

In this extract Wendy seems to suggest that she felt objectified whilst her body was being scrutinized by various medical professionals. It seems that her opinion was not

solicited and the surgery she had was discussed as a 'good job'. Young (1990) argues that there is an assumption that all women aspire to the cultural understanding of a 'perfect breast' therefore Wendy struggled with the clash between her preferences for breasts that were perceived to be 'imperfect', yet felt good to her, and the expectation that she would want an 'improved' bust. Wendy continued:

And it was a bit of back-slapping and again I don't mean to be too critical because they were wonderful people. I'm being perfectly honest about what I felt now and er I wish somebody would have just said 'I'm sorry that you haven't got the breasts that you had and I'm sorry that this has had to happen to you' but it was, 'are you pleased with it?' and I didn't know quite how to react to that. Well 'I'm pleased that you've chopped the cancerous bit out, I'm pleased that I don't look [pause] too disfigured, but you know actually I'm not pleased that it's all happened and I'm not pleased that you've had to do it'. But I never said any of that then.

The surgeons' reported comment 'are you pleased with it?' suggests that they are just referring to the cosmetic side of the operation rather than the reason behind it, yet the reason behind it is what was most important to Wendy. It seems to be ignoring the reality of the breast cancer and concentrating on the 'boob job'. Young (1990:201) argues that the transformative possibilities offered by medicine have given rise to an attitude of 'why wouldn't a woman "choose" perfect breasts when the opportunity is there?' but Wendy reported how she felt when people implied that she should be grateful for having this 'opportunity':

I did get that a lot, 'people have to pay for this'. You wouldn't believe how many people said that. Even a few nurses said that, 'some people pay a lot of money for a boob job!' and I was expected to smile and laugh at that and I think 'no'. No absolutely not.

The assumption that women should be more concerned with the cosmetic side of treatment was highlighted by Peters-Golden (1982) who interviewed 100 breast cancer patients and also 100 'healthy subjects'. She found that the latter group believed that the loss of the breast would be the most distressing aspect of the experience whereas the women who had been treated for breast cancer reported that such concerns were secondary to the experience of having had a life-threatening illness. These arguments will be developed in the following chapter which will look at interpersonal relationships and the public perception of what is considered appropriate behaviour of women who have been treated for breast cancer.

Chapter summary

This chapter has shown how women's bodies are intricately enmeshed with their self-concept, self-confidence, femininity and sexuality. Consequently, treatment for ESBC/DCIS can have implications for current or potential interpersonal relationships which may be affected by the way a woman looks and feels. The cases that I have highlighted are indicative of the issues faced by women who have permanent embodied reminders of their experiences. It was discussed how the breast has different meanings to different women and thus loss of the breast(s) can be experienced in various ways

depending on whether breasts are viewed as gendered, functional or sexualized (Langellier & Sullivan, 1998). Some participants reported that they were able to reconcile the loss of their breast by comparing it favourably with a more vital body part (i.e. it was less problematic to lose a breast than an arm or leg). Others however considered their breast to be an intrinsic part of their womanhood and expressed difficulty in coming to terms with its loss.

Even when they have been able to accommodate the changes to their bodies, it appears that to varying degrees they are all living with a 'new normal' body. Participants not only talked about how they felt about losing their breast(s) but also other people's reactions to their bodies which could affect current or potential intimate relationships. In some cases, fear that they may be rejected by potential partners or be stigmatized has added to the general encouragement that women with breast cancer receive to normalize their appearance. Participants who chose to do this either used prosthesis or underwent reconstructive surgery. Most participants who had reconstruction reported that they were happy that the surgery had restored a 'normal' appearance when clothed. However, some participants seemed to have higher expectations and were disappointed with their reconstructed breasts when naked. In addition, some of the women highlighted a loss of sensation and an unnatural feel. There are further drawbacks of normalization. For example, restoring a normal outward appearance can mean that people forget or don't know that women have been through this sometimes traumatic experience and this can result in further consequences for relationships. This will be discussed in the following chapter where I will explore what the 'new normal' entails in respect of

interpersonal relationships in the aftermath of treatment for
ESBC/DCIS.

Chapter 7 Living with a new normal part

2: Intersubjectivity

Introduction

In the preceding chapters I have considered the disruption to women's lives as a result of a diagnosis and treatment for ESBC/DCIS in line with Bury's (1982) theory of illness as a biographical disruption. I have also extended this theory to the post treatment period to consider the further disruption during the transition from the sick role as described by Parsons (1951) to establishing a 'new normal' (Mukherjee 2011b), which I have described as liminality (see chapter 5). Part of Bury's (1982) theory posits that biographical disruption encompasses finding meaning in the illness. In chapter 4, I discussed the ways that participants tried to establish an explanation for their illness within their life histories, which Bury describes as meaning as significance. I then began the discussion of meaning as consequence in chapter 6, by considering the effects of ESBC/DCIS and its treatments on women's bodies, confidence and intimate relationships, as well as the steps that were taken to mitigate these changes. The current chapter will extend the discussion to consider consequences for interpersonal relationships, because as Anderson & Bury (1988) argue, social responses to illness have far-reaching and long-lasting effects on experiences. As with all interpersonal exchanges, this is a two-way process. First there is the effect that the woman's illness has on the family and her wider social network. Secondly there is the

way that women's illness experiences are shaped by their relationships. I will therefore present a sociological perspective of the complexities involved in the experience of breast cancer, grounded in the viewpoint of the women who I interviewed, of what it is like to live with and beyond ESBC/DCIS.

The chapter will begin with a focus on motherhood and domestic roles. Although all manner of relationships were discussed by my participants, these seemed to be central to women's identities and therefore most pertinent when considering the gendered nature of biographical disruption (Bury, 1982). This reveals the interpersonal and gendered aspects of biographical disruption which Wilson (2007) argues is missing from Bury's (1982) original concept which was developed in his study of the impact of rheumatoid arthritis on people's lives.

After considering the impact of illness on the immediate family I will move on to describe some of the experiences reported by my participants of practical and emotional support that they received from their family and wider social network whilst undergoing treatment. I will also describe their reports of instances where this support either failed to materialise or was not experienced as appropriate, with reference to Goffman's (1963) theory of stigma in interpreting the participants' accounts of their illness experience. Part of this discussion will focus on the way that participants reported having to 'manage other people' both during and after treatment. This includes monitoring the type and amount of information they revealed and I will be drawing on Hochschild's (2003) concept of emotional labour to explore how and why they did this. The public perception of breast cancer including the positivity associated with survivorship and the plethora of pink-themed

charity campaigns will also be discussed in relation to the impact it has on the responses felt to be appropriate for women with ESBC/DCIS.

I will then move on to discuss the role of other women with breast cancer, who in the main were perceived as very helpful. Relatedly, I will present evidence of how the participants have reported subsequently using their experiences to reach out to other women with breast cancer, including their willingness to contribute to the current research. However, there were also problems associated with assuming a commonality of experience. This was particularly pertinent for my participants whose breast cancer was discovered at an early stage and who felt very different to women whose cancer was more advanced. The implications of this for seeking support will be discussed with reference to the mixed reactions reported by participants ranging from thankfulness to survivor guilt. Finally I will highlight the challenges of negotiating a 'new normal' amongst these competing attitudes.

Biographical Disruption and Motherhood

Motherhood seemed to be central to many of the participants' breast cancer experiences. As an indication of its importance, when I revealed my own breast cancer story to the participants, the most commonly asked question was about how it had affected my two sons who were 9 and 11 when I was diagnosed. This was not only raised by the women with young children themselves, but also the women who either had older children or none, who often reported that they felt their situation would have been worse if they had had young children to consider.

Nine of my participants had children living at home at the time they were treated for cancer and the effect of their illness on their family formed a major part of all their narratives. For example, when she offered to take part in the research, Catherine's e-mail read:

Having breast cancer is a huge experience and has affected my life and the life of my family profoundly (e-mail, 31/1/11)

Wilson (2007) who considered the effects of HIV on mothers' identities argues that previous studies of biographical disruption, as well as illness studies generally, have neglected gender and concentrated on individual responses. However, Catherine's comments illustrate how women did not just have their own distress to deal with but also had to consider the effect of their illness on other family members. This was also highlighted by Wilson's study and specifically relates to the perceived need to survive for the sake of their children. In the current study the threat to women's roles as mothers was felt most acutely when they were first diagnosed and did not know their prognosis. For example Viv, whose children were 11 and 13 at the time, echoed the feelings of all of the participants who had young children when she said:

Having young kids was the worst thing. Cus you just think, the kids still need me. If I die now my kids are [starts crying] Yeah that's the worst thing, your kids.

Viv expressed fear that if she was to die, there would be nobody who could fulfil her role as her children's mother. This was the time when many of the participants became upset when they were recalling their experiences. It seems that the responsibility of having young children had compounded the

distress caused by the breast cancer and in this respect, their identities as mothers were particularly vulnerable to disruption. Although Viv reported that concern for her children was 'the worst thing' about it, this was becoming less of a worry as time went on:

It gets better as your kids get older. Like my daughter's 18 now, she was 14 then..so that's easier because they get - they're not so dependent on you anymore are they? She'll be off to university.

This comment suggests that Viv's role as a mother was less significant once her children reached 18, i.e. the culturally accepted age of independence. Wilson (2007) argues that in the case of her participants, the dependence of their children presented a moral justification for the mother's continued survival although they feared having no purpose once their mothering role was no longer needed. However, other participants in the current study reported distress experienced by older children. For example Jean, whose breast cancer experience happened 29 years ago, spoke at length about the impact on her then teenage children. She described how her daughter, who had just started to train as a nurse, had reacted particularly badly:

I spent about two years picking Jenny off the floor. That made me not think about myself.

Jean explained that as her daughter was working on a cancer ward at the time, her experience was that many women diagnosed with breast cancer would die. Jean's comments suggest that her mothering role had taken over and she prioritised looking after her daughter rather than concentrating on her own distress. Catherine elaborated on

this theme in her narrative as she reported that during her illness her main concern was for her family, specifically the effect that her treatment had on her son who was 11, at the time:

It affected the family considerably. My son has always been a very energetic boy and potentially he could have been diagnosed with ADHD but he hadn't been, but he was subsequent to this. Because he started having really bad panic attacks. And that was because of this. And school didn't, didn't cut the relevant slack...Basically every time I went into chemo, Adam was extremely anxious and tense. And so the normal stresses and strains of school were becoming overwhelming for him. So just normal children stuff like teasing, you know, like throwing things at one another, he was overreacting because he was very, very stressed.

It seems that despite her own need for support, Catherine found herself providing support to her son because she reported that his emotional distress was not addressed by his school. Catherine speculated that his disruptive behaviour resulted from his anxiety over her treatment, thus indirectly taking responsibility for her son's actions. When I interviewed Catherine, her son was in the house because he had been excluded from school. This indicated that the family were potentially still suffering repercussions two years after her treatment, and although cancer had affected just one person, the experience had impacted on all the family members.

Some of the participants who had children living at home with them reported that they felt a responsibility to act in a certain way in order to protect their children. For example, Carol

reported that her 15 year-old son had said 'You've got to get better, I'm doing my GCSEs' and asked her not to 'ever cry'. Therefore she reported:

I have to sort of hold it in then sort of cry afterwards. I cry at films..or seeing other people ill.

As a result of her son's comments, Carol reported that she had hidden her feelings, although her distress seems to 'leak' in other circumstances, such as empathising with other people who are ill. Carol is displaying the 'emotional labour' (Hochschild, 2003) involved in protecting her family. This is defined as 'suppressing feeling in order to sustain the outward countenance that produces the proper state of mind in others' (Hochschild, 2003:7). By hiding her distress, Carol was able to preserve a facade of normality and minimise disruption to the family at an important time in her son's life. However, Hochschild argues that emotional labour comes at an emotional cost because 'it affects the degree to which we listen to feeling and sometimes our very capacity to feel' (Hochschild, 2003:21). This will be discussed further later in the chapter.

In contrast to Carol, another participant, Maggie, reported that she believed her son was not unduly concerned:

I think my son who was 9 at the time, I thought he wasn't really affected by it you know you make these wrong assumptions about children but actually his teacher told my husband that he'd been crying in class. Um though I hadn't seen any sign of that myself. He was being sort of cheerful all the time.

Maggie's experience disrupts the idea of mothers hiding their anguish from children. In her case, her son was presenting himself as 'cheerful' at home, but becoming upset at school, suggesting that it was he that was doing the emotional labour. This resonates with the findings of Forrest et al (2006) who interviewed 37 women who had been treated for breast cancer and also interviewed their children separately. They found disparity between their accounts, with mothers sometimes reporting that they felt their children were unaffected, whilst the child reported being upset and concerned. Forrest et al argue that judging children's reactions can be difficult. If children hide their distress by becoming detached parents may mistakenly assume that they are not concerned by their mother's illness, which seems to have happened in Maggie's case.

Although the role of mothers was likely to be disrupted through illness, their nurturing role was a biographical continuity. In this respect, there were similarities between my participants and the women affected by HIV infection and illness who were interviewed by Wilson (2007), in her study of motherhood. Women did not stop caring for their children, even if their predicament meant that they were unable to play such a big role in their children's lives. To this end, they tried as far as possible to keep up with the normal routines of family life which was also comforting for both them and the children. One of my participants, Karen, who had two sons aged 12 and 14 was in the midst of treatment when I interviewed her. Karen acknowledged that her sons had been affected on an emotional level but explained how as a family they had tried to retain a sense of normality to try to minimise

the upset that it would cause. She told me that as far as her children are concerned:

Life is going on normally..they get told off if they're not doing what they should be doing..it's running as it did before, the household really so it's, in that respect it's minimal effect on them.

Karen's description of maintaining routines and not treating her sons any differently indicates that when other facets of their identity had been disrupted, motherhood provided a way for women to preserve an important aspect of their pre-illness identity, a finding that Wilson's (2007) study also supports. Similarly, in a recent Australian study, Fisher & O'Connor (2012) interviewed eight women in-depth, four times in the first year after diagnosis of breast cancer. They argue that maintaining normality was mutually beneficial; not only did it minimise the disruption to children's routines but also it helped women to have a biographical continuity. In their study, as in mine, sometimes retaining normality meant that other people had to assume some motherly duties, but this had emotional consequences as Maggie described:

It was towards the end of term ..at that stage they had concerts and all sorts of things to which obviously my husband was quite capable of doing it but I also wanted to be there you know so that was quite upsetting as well.

Maggie is revealing how it was in the minutiae of family life that disruption to her mothering role was felt most acutely. As her daughter was 11 at the time, the end of term events she referred to also marked the end of primary school which is an important landmark in a child's life, and which Maggie apparently missed out on. Consequently, it seems that Maggie

was distressed at being unable to fulfil the social requirements of motherhood even though her husband was able to assume some of her responsibilities. She went on to tell me about the difficulty of seeing her husband struggling to care for them while she was ill:

When I was diagnosed .. it was the year after we'd moved so I didn't have the support network here that I would have had in London and ..although people were all very helpful, we didn't know so many people that we could sort of offload the kids on and that sort of thing. So that side of it was quite difficult. I think my husband- at the time it was almost as difficult for him because he had worry about me and looking after me and he had to deal with the children. He was working full time and he didn't have a particularly sympathetic manager either.

These comments reveal gendered aspects of the experience which are echoed by Emslie et al (2009) in their study comparing the narratives of equal numbers of men and women undergoing treatment for bowel cancer. They found that women provided detailed descriptions of their arrangements for childcare and domestic labour whereas the male participants with dependent children did not discuss this aspect of their experience at all. Emslie et al (2009) argue that this reflects traditional gender roles where women's primary concern is the welfare of others. Maggie is conveying her guilt about burdening her husband with household and childcare tasks in addition to working full-time and worrying about her. Maggie's experience also underlines the importance of having a network of social support to draw upon in these circumstances, which will be further discussed in the following sections.

Domestic roles

Social support describes both practical and emotional support, many instances of which were revealed in my participants' narratives. Some participants reported that they had been quite ill as a result of chemotherapy and all of the participants had undergone surgery to one or both breast(s).

Consequently there were restrictions on their activities, even to the extent that they were advised against lifting a filled kettle. Some of the participants reported that relationships with husbands or partners had changed where they had taken on the caring role during the time that the women were ill. For some participants, particularly the older ones, it appeared to have been the first time that husbands had been required to perform household tasks and it seemed to provoke defensiveness in their wives. For example, 63 year-old Joy told me that she was not allowed to do heavy work in the home. Consequently, she had to rely on her husband to do it:

He used to stand ironing and .. all the while he was doing it I was thinking 'ooh you're not doing that right'..[laughs] But I mean bless him, he did try. But they tend to smother you. But now he can cook dinners he always has been able to but he's never, I think it's an art a woman's got to be able to get everything together and it comes on the plate at the same time.

Despite claiming to value the care that her husband took of her, Joy devalues his efforts (although she did not verbalise them to him) by thinking to herself 'you're not doing that right'. Clearly, Joy views domestic duties as her area of expertise, claiming that the ability to ensure that everything is

ready at the same time is 'an art a woman's got'. This perhaps reflects the more firmly entrenched gender roles of the older participants in particular, for whom the switching of domestic roles was experienced as disruptive. After their treatment ended, most women reported that domestic roles had reverted to the previous status quo, although that was not always welcomed as will be seen in the next section. But for Barbara D, there were continuing frustrations because of the context in which she became ill. Barbara reported that her husband had retired whilst she was having treatment and immediately assumed the domestic role and cared for her. They had suffered a major disruption to their everyday routine and this was experienced as a further challenge once Barbara was well again, when she wanted to leave behind the passive sick role and reassert her position within the home. She told me:

He's been excellent about it. He's been very supportive. I mean I've made things very difficult sometimes erm I don't think I'd have got through it properly without him. In some ways he was worse than me. He did find it hard, ever so hard. Especially when they've been out to work all their lives, they're so used to you sorting stuff out for them then all of a sudden they've got to sort it out. And I think the biggest challenge we've had because Ken took over when I wasn't well and then when I was better again I wanted to do more and he found it difficult to sort of take a back place..he retired when I was having chemo. He finished work when I got this and so yes it was quite a big thing. We've both had to do quite a lot of changes. Because I'd been used to having the house to myself and all of a sudden we're sharing bits, differently to what we normally share.

Barbara is showing mixed responses in this excerpt. She is very grateful for her husband's support in undertaking responsibilities seemingly for the first time, but reluctant to share the domestic space once she got well enough to resume her role. Retirement can be a difficult period of adjustment for couples in any circumstances but it seems that the previously clear divisions between Barbara's and her husband's roles had become blurred during Barbara's illness. This seemed to have created tensions between them which, until they can renegotiate roles and occupation of the domestic space, appears to be an issue that is yet to be resolved. Emslie et al (2009:1174) argue that 'for many women, caring responsibilities are intertwined with identity'. Both Joy and Barbara demonstrate from their comments that they feel their identity as homemaker has been irrevocably disrupted because their breast cancer experience coincided with their husband retiring. It also may explain why Joy reported that her husband spent much of his time in the shed!

Not only did partners help with domestic duties but participants offered examples of other people who had responded by offering practical support. For instance, Ruth reported that her husband had mustered support from the local community and organised a rota of people to cook meals for them both:

My husband was fantastic, absolutely brilliant. He's a great organiser my husband, he got in a bit of a panic because he didn't think he would be able to do all the cooking but I only wanted to eat certain things. Like when you're pregnant, you know. And what he did was he organised all our friends and neighbours to do

cooking! [laughs] but they liked doing it and it meant that he didn't have to do the cooking every night.

This is an illustration of Bury's (1991) argument that a common response to illness is to mobilise resources. Ruth said that people had welcomed the chance to help. People often feel helpless when on the periphery of a trauma so doing something helpful can also be beneficial to them. However, sometimes these offers of practical help were not welcomed. For example Kate told me that her mother visited regularly to do her housework:

I couldn't keep her away. And I had to let her do it. Because she felt that she was helping me but I know that I was helping her.. Because I just wanted her to go away.

Kate seems to have resented her mother's assumption that she could not do the housework and the subsequent loss of control of her domestic role. Goffman (1963) argues that it is a requirement of the stigmatized to accept help gracefully, whether it is needed or not, in order to maintain the social situation at hand. In this case Kate's mother wanted to care for her and Kate tolerated it for her mother's sake, even though she reported that she found it irritating.

Emotional support

In terms of emotional support, without exception, participants spoke warmly of receiving numerous phone calls, visits, cards and flowers from family, friends and colleagues. Speaking of his own experience of testicular cancer, Frank (2002:79) reflects: 'these messages in particular gave me what I think ill

persons need most, a sense that many others, more than you can think of, care deeply that you live'. This was Joy's experience:

The house had always got somebody in it. I mean when I came home, there was always somebody there..or somebody was coming. Even if it was only 'hello, are you alright?' and go, there was always somebody there..Cards! I've never seen so many cards. And it was showing that you know people cared. But [pause] it suddenly goes don't it?

Although appreciative of the emotional support she had, Joy's last sentence reveals a common experience, that social support was withdrawn soon after the end of treatment. Barbara D summed up the feelings expressed by many of the participants when she told me:

You do actually feel let down. You've had this, sort of everybody was interested in you and looking after you and then all of a sudden it's all over. Enjoyed feeling special. Perhaps cus we're not used to being looked after.

Barbara seems to be suggesting that a woman's role is to look after other people, which reinforces Hallowell's (1999) argument that women tend to put others' needs before their own. Barbara appeared to have enjoyed a respite from responsibilities afforded by the sick role (Parsons, 1951) where she was the one who was 'being looked after' for a change. It is notable that Barbara appears to contradict herself because, as previously discussed, she had reported that she wanted to resume her domestic duties. However, she seems to be missing the attention she had received which had made her feel 'special' because people were 'interested' in her.

Another participant, Viv, reported that she believed that her role in the family prevented her from getting the emotional support she needed:

My mum and two sisters came every day to the hospital and brought me food and stuff. And came every day when I came out. My sister came and cleaned the house, did the ironing, washed my hair and everything cus I couldn't after the operation. So yeah they were good. Yeah, quite caring. But I suppose I'm quite self-reliant so they probably just think 'oh she's alright. It's past now, it's finished so why talk about it? it's over' so

D but you'd like them to say 'how are you feeling?' kind of thing?

V yeah but I suppose we don't anyway.. You know, my sister and my mum do [laughs] but I never have really so, I suppose it's what they expect from me. So just carry on like that. Suppose you do don't you? You get a role in your family and it sticks

Although Viv acknowledged that she had previously been quite independent, she seems to have enjoyed the close relationships during her illness which included not only practical support with cleaning and ironing but more intimate care such as washing her hair. Her comments indicate that it was not just practical help that she needed, but also emotional support, which seems to have been withdrawn at the end of her treatment. Viv speculated that she was expected to resume her former 'role' as self reliant, whereas she seemed to envy her sister's close relationship with her mum. This suggests an assumption of a fixed identity whereas Mathieson & Stam (1995:299) argue that 'a diagnosis of cancer

challenges older self-narratives and motivates the search for newer narratives that incorporate the meaning of illness'. Although Viv sensed a new narrative had emerged which incorporated a need for closer relationships with her family, her assumption that her mother and sister are unwilling to talk about her cancer because 'it's finished' seems to have prevented her doing so. Consequently, Viv seems to have reacted defensively:

I think it's made me more self-reliant. Cus you know, you are on your own aren't you? It makes you face up to that a bit...I feel a bit more [pause] that you've only got yourself. Even though he [husband] was really good, he was really nice but [pause] you have only got yourself. You're the one going through it. You're the one in the hospital having stuff done. If you die, you die alone don't you? So yeah I think it has made me a bit harder.

In this moving account, Viv conveyed her sense of isolation once the intensive period of treatment and consequent social support ended. This is confirmed by studies of the role of social support which suggest that women who receive appropriate support tend to cope better (Chou et al, 2012) whereas women who reported that the end of treatment coincided with a loss of support struggled to cope with family, work and social responsibilities (Allen et al 2009). Similarly, Viv seems to be struggling to cope due to the withdrawal of support from her family and the failure of other people to understand how she had changed as a result of her experience.

Another of my participants told me how she believes that this attitude is understandable, if upsetting. Speaking about how

her adult children had been very supportive during her treatment but afterwards reverted to their old ways, Ruth said:

I think the difficult thing about relationships is that when you get better, they revert to normal whereas you're a changed person. Do you know what I mean? You've been through this awful trauma, this life-changing experience and you've changed inside but they haven't and so they just revert back to normal.. they were great during the illness but I think it's a funny thing isn't it when you expect people's attitudes to change towards you but why should they change? You know. They assume you're normal again. To all intents and purposes I am really.

Here, Ruth was directly attributing her changed outlook to the 'awful trauma' of having been treated for breast cancer whilst trying to reconcile her disappointment that other people have reverted to a 'normal', which she feels that she no longer shares with them. The simultaneous withdrawal of medical and emotional support seems to have had severe consequences for Ruth who reported:

I had terrible terrible depression afterwards and I think it was when normality resumed really ... instead of having all this wonderful nursing care, like the district nurse popping round, going into hospital and being treated like an invalid, ... Suddenly all that starts to fall away..friends resume their normal habits instead of being really sweet to you they're back to normal again which of course they should be, you know you don't want them hanging around saying 'are you alright?' But you suddenly feel incredibly left on your own.

This is a rich quote which conveys the mixture of emotions Ruth was feeling after her treatment. She told me that she had been very ill as a result of chemotherapy and she then had three weeks of radiotherapy which entailed a five hour round trip, three times a week. However, once her treatments had ended, Ruth seemed to have missed the benefits afforded by the sick role (Parsons, 1951). Although it meant that she was no longer ill, it also induced a sense of isolation after being the subject of attention from medical professionals as well as friends and family. Whilst acknowledging that it is natural for people to go back to normal, she feels that it is easier for those around her to do so because they have not been through what she has. And the frustration of this seems to be something she cannot express. It is possible that Ruth is demonstrating the costs of emotional labour (Hochschild, 2003) because, as will be seen later in this chapter Ruth reported that she was not always entirely honest in her encounters with other people. As was mentioned in chapter 5, Frank (2002) argues that ill people expend a great deal of effort in maintaining appearances for the sake of other people. However, Frank also believes that this comes at a cost because they miss out on sharing honest experiences with those who care for them. It seems that dishonesty, even when done for good intentions can be detrimental to relationships; as Ruth's case shows, it may also have implications for forming 'new normal' relationships. This will be further discussed in the following section.

Biographical disruption and relationships

Sontag (1991) argues that a surprising amount of people with cancer find themselves shunned by friends and relatives,

perhaps because cancer has a history of concealment and there remains some stigma attached to having the disease which is still associated with death. As discussed in chapter 2, the breast cancer patients in Peters-Golden's (1982) study reported that sometimes friends or family members avoided them and the 'healthy' individuals admitted that they often avoided people with cancer because it increased their own sense of vulnerability to death and dying. In the current study, some of the participants' narratives seemed to exemplify many of these intersubjective tensions. As Malaika said:

You see relationships in a different light, you see yourself in a different light, you see your whole life in a different light. It's like an electric lightbulb just pinging on and you know everything shining and everything being illuminated and we have to see everything whether you want to or not.

Bury (1982) argues that illness reveals starkly the true nature of relationships, and the way that Malaika describes it, the experience of having breast cancer revealed the good and bad things about her life. By implication this is in contrast to others around her who retain the option not to see everything. Their failure to see may then become consequential or problematic. For instance, although the majority of my participants reported that their relationship with their husband or partner was stronger as a result of their experience, Gabrielle reported that her marriage was damaged irrevocably:

My illness exposed finally for me that my husband ..just wasn't a coper..and he hijacked my illness. My illness became about him and how he could get sympathy from people. You know 'I love her so much' and 'I don't know

what I'll do if anything happens to her'. But the reality was that he didn't do anything for me other than talk about my illness to get sympathy..and it's harsh; but that was my reality of it...Sadly my relationship did not survive my recovery .. cancer **is** life changing. I looked at it and I thought I can't do this anymore. And it kicked off more pain and drama almost more than the recovery from cancer in a way because I had been with my husband for about 26 years and it's been a very painful experience.. So it was the catalyst for change but the change and the fallout was harder than dealing with the cancer.

In this excerpt, Gabrielle is drawing on a common trope within the public understanding of cancer which is often portrayed as a springboard for change. For example, Seale (2002) studied news reports of people with cancer and argues that they often feature cases of people overcoming adversity to triumph in some way or other. However, in Gabrielle's case it does not seem to have been a wholly positive experience. Gabrielle reported that she knew that she could no longer be with her husband because of his reaction to her breast cancer diagnosis, thereby attributing the blame for her marriage break-up to her illness and her husband, even though it seems to have been her decision. Consequently she told me that the worst part of her experience was after her treatment had ended. This supports the argument which began in chapter 5 that ESBC/DCIS does not occur in isolation therefore it is important to consider the context of illness within the participant's life story. In another example, Connie's diagnosis of breast cancer came within the context of living with and caring for her mother who Connie described as 'a very strong character [who]

still thinks I'm about 3!' When I asked Connie how her mother had reacted to her illness she said:

It was more about her 'oh, it's making me ill!' [laughs]
But don't you think it's that generation?

It seems that rather than offering support to Connie, her mother was blaming her for her own ill health. Additionally, Connie reported that she was caring for her older sister at the time she was diagnosed with ESBC. She told me:

My sister finds it [pause], she lost her husband in the August and she's 10 years older than me. And she was finding it very difficult so I used to cook her meals and so forth. And then when I was diagnosed in the December that sort of obviously stopped and I think she found it all quite difficult. And our relationship, I hardly saw her all the time I was having the treatment, you know she found that difficult to watch me. That was difficult. I suppose I clung to the few close friends I've got because they [pause] they're actually willing to talk.

Even though Connie reported that she had supported her sister both practically and emotionally after she was bereaved, it seems that the support was not reciprocated during Connie's treatment. Connie excused it by speculating that it was difficult to watch Connie suffer so soon after the loss of her husband, just as she had excused her mother's attitude as typical of 'that generation'. The hesitant speech at the beginning suggested that she was feeling the need to justify her sister's behaviour. Connie uses the word 'difficult' three times when describing her sister's perception of events and again when describing her own experience of needing support which was not forthcoming. It seems that her friends had

stepped in to provide support that was missing from her family who Connie implies were unwilling to talk about her experiences as they were too caught up in their own problems.

It seems that many people are unprepared for withdrawal of support from others they had assumed they could rely on, as in Catherine's case. She told me:

Some people surprised me because they sort of just bolted off and wouldn't do anything. And one of them was my brother who I was very close to and he just couldn't hack it at all. Which was really weird. We've only just started to get friends again. I'm not holding it against him but at the time it was quite painful because I would've liked for him to be around. We're just getting close again now.

Instead of offering care and support as Catherine had anticipated, she reported that her brother had withdrawn from her life when she needed him most. Frank (2002:103) believes that this is an example of the ultimate denial of an ill person's experience. He argues that 'in disappearing, they deny that anything special is happening or, alternatively, that the ill person exists at all'. This is the flipside of emotional support, which as mentioned previously, confirms that 'others care deeply that you live'. Consequently, Catherine seemed to be struggling to rebuild her relationship with her brother. Scambler (1997) describes this overt reaction as enacted stigma because people are openly displaying their unwillingness to engage with someone who has a stigmatizing condition. This was illustrated again in the current study, by Malaika, who described a friend's reaction to her illness:

One of my close friends at the time, and she's not a close friend at all now ,I don't have anything to do with her, my daughter said "you've not been up to see my mum at all and it's been nearly 3 weeks. You know she's in hospital and you've not seen her since her diagnosis". And she went "I can't deal with it! I don't know how to deal with it" and my daughter said "how the fucking hell do you think my mum's dealing with all of this?" And it was ironic how many people fell apart. And there were other people who "I was scared you were gonna die. I couldn't come near you."

Malaika describes it as ironic that her healthy friend was expressing distress when it was Malaika who was undergoing the treatment. It seems to support Sontag's (1991) argument that because cancer seems to strike indiscriminately it 'arouses thoroughly old fashioned kinds of dread.. [and] will be felt to be morally, if not literally contagious' (Sontag 1991:6). It seems that there are competing discourses surrounding breast cancer and its treatment. On the one hand there is the illness discourse with its emphasis on the negative impact of treatment on the body and femininity as well as an underlying threat of death from the disease. The prevailing idea that cancer = death influences the reactions of other people as seen in the above extracts. However there is another discourse which encourages positive thinking and has led to the association of breast cancer with pink, fluffy imagery, as mentioned in chapter 1. The effect of both of these discourses on the participants' dealings with other people will be discussed in the following section.

Self-censorship

As was seen in the previous section, the association of cancer with death can have a negative impact on even the closest of relationships. Consequently, participants revealed how they felt constrained in their interactions about the type of information they were able to share. This is illustrated by Karen's experience:

When seeking support in the early days and now, it was often me that ended up supporting others. Two of my friends on visiting me after the mastectomy cried when they saw me and I needed to reassure them. After this I felt the need to put on a 'brave' face and minimise what was happening to me to protect them. I guess this is what I have done in all my relationships, in and outside the immediate family. (e-mail 19/5/11)

Karen describes how she prioritized her friends' needs for comfort and reassurance over her own. Hochschild (2003) argues that this is a particularly gendered aspect of emotion work because women tend to show deference. However, she claims that this is not due to an innate characteristic in women, but because to a certain extent women are dependent on men. Similarly, ill people are dependent on others for medical, practical and emotional support therefore my participants have increased reasons to act in this way. Hochschild (2003) further argues that because in our culture women are traditionally seen as the ones who care for others, there is a danger that they can become overly concerned for the needs of others at the detriment of their own needs. For example, Ruth who as I described earlier, had been very ill during her

treatment and subsequently suffered depression, sent me an e-mail after I had interviewed her with an afterthought:

The other thing I found was that people only want to hear good news, if I started to tell people how much something hurt or how dreadful I felt, then they sort of backed off. So I only ever told them good things as that's what people want. The public don't like a moaner! (e-mail 12/2/2011)

This is interesting in the context of Ruth's comments discussed earlier where she complained that other people did not understand how she had changed as a result of her experience. Ruth seems to have been more concerned with sparing other people's feelings so that they would not 'back off' and is paying the price for it because (perhaps unsurprisingly) people were under the impression that she was 'back to normal' which she complained about in the earlier citation. The 'good things' that Ruth refers to are described by Kelly & Field (1996) as public accounts which tend to be expressions that people feel they 'ought' to use. This is in contrast to private accounts which are 'difficult and socially unacceptable' aspects of illness which tend to be at odds with the public account (Kelly & Field, 1996:250). Similarly, another of my participants, Joy, described another instance of a public account, telling me that she would always say 'I'm fine' when asked how she was:

You only tell them so much because you think 'oh god they don't want to hear this' and you know if anyone ever says to me "how are you?" I always say, 'I'm fine!' Now Pam, she used to say 'No you're not! Why do you say you are?' and if somebody said 'hello Joy, how are

you?' I'd say 'I'm fine' and Pam would say, 'she isn't really, she'll tell you she's fine, she tells everybody she's fine'. But what can you say? What can you say? Well I am fine. You can't really say 'oh I don't feel very good today' well that's depressing. I mean I have felt depressed, I've felt that sometimes I could scream you know.. when I've thought about it. But it's just one of them things isn't it? You've just got to gerron with your life.

It seems that Joy did not want to burden other people with her problems and felt a need to project positivity. Sacks (1975) talks about this phenomenon in his essay 'Everyone has to lie'. It is the socially acceptable reply to the question 'how are you?' which tends to be used as a greeting rather than a serious enquiry into the state of someone's health. Sacks argues that a reply such as 'oh I don't feel very good today' would have initiated a conversation, since the follow up would be 'why?' or 'what's the matter? It seems that Joy has realized that there are conditions on what can be said and what cannot, what is 'speakable' and what is not, and the answer 'I'm fine' stops the conversation progressing. Even though she sometimes felt 'depressed' and that she could 'scream' Joy seems to have put on a front for the sake of other people (Goffman, 1959). Both Ruth's and Joy's experiences echo the findings of Peters-Golden (1982) where former cancer patients reported that they had to learn how much information they were able to divulge without upsetting other people.

Because of these implicit rules, if someone insisted on talking about their cancer, it seems that they were expected to do so in positive terms. Nevertheless it seems that Joy perceived

such an attitude to be appropriate for talking about her experiences, judging by the fact that she repeated phrases such as 'life goes on' and 'you've just got to gerron [get on] with it' nine times during her narrative. However, examining the context of the talk in which such comments appear reveals that they were often used as a device to enable more distressing aspects of the experience to be discussed. For example:

I still have the odd tear but you know you've just got to gerron with your life, it's like everything else. But as I say I am fine, I am;

I mean it is a life threatening thing but you just have to get on with life don't you?

This type of talk was examined by Wilkinson & Kitzinger (2000:805) in their discourse analysis of interviews with women with breast cancer. They argue that such comments are a conversational device used as an "upbeat" end to 'round off and close down "troubles telling," and thus relieve the listener of the burden of hearing about unpleasant experiences or having to find a solution. They further argue that such talk is a way of fulfilling a 'socially normative moral requirement' to be positive through the experience of having breast cancer. This echoes the argument of former breast cancer patient Barbara Ehrenreich (2009) who strongly criticises the impetus of positivity that has permeated breast cancer culture philosophy. She argues that it pressurises women to think positively and ignores the horrors of the disease. In her examination of psychological literature surrounding positive thinking and cancer, De Raeve (1997) argues that positive thinking seems to serve others who are finding the bad news

hard to cope with rather than the patient, and the recommendation to 'think positively' can be insensitive. For example, broadcaster Jenni Murray recalls a friend extolling the virtues of 'the power of positive thinking' even as she tried to explain her fears about surgery, radiotherapy and chemotherapy. The refusal of the 'friend' to acknowledge these natural feelings was felt as a rebuttal (Murray, 2010).

Nevertheless, as was discussed in chapter 1, breast cancer charities and their corporate sponsors present a 'pink, fluffy' face of breast cancer to the extent that the pink ribbon which symbolises breast cancer charities is now a ubiquitous part of everyday life (Kaiser, 2008). This is how one of my participants, Karen, talked about it:

But what I do hate is the pinkness of it...I have to appreciate that if that's what gets the money rolling in that's the marketing side of it, but it's the pinkness that [pause]. When you read about women, especially when you can see on the forum so-and-so died aged 42, there are women on there that are 21 with breast cancer, and the pink fluffiness of it is quite annoying because I don't think it's taken quite seriously enough and just what, you know, what a nasty disease it is really. So I'm sort of, I don't do anything to do with pink fluffiness or people try to get me involved in things like that I'm sort of, I'm silent really because I just can't, can't do it ... but they need the money so I can appreciate... and what is it Asda do? 'tickled pink' or something? Oh god!

Karen veers from negative to positive statements throughout this segment, which clearly illustrates the conflicting feelings experienced by women who are actually affected by breast

cancer. This was highlighted in the narrative of Andrea, who said that as a lesbian, the ultra-feminine marketing associated with breast cancer campaigns was the complete opposite to her way of life:

There's people still living with it, people still dying of it, lost their children because of it you know. And it's just too rosy. ..and all of the symbolism that's the bit you know the pink triangle used to be associated with gay but then you have pink for breast cancer and of course pink for girls thing which is probably (pause) you know, for someone like me..

Andrea's comments highlight how many women do not identify with the pink, fluffy face of breast cancer. In addition, men affected by breast cancer may see it as a reinforcement of the idea that they have a woman's disease.

It seems that participants had to self-censor in the name of protecting loved ones, keeping a public appearance of positivity, and so on. However, self censorship can also be a way of managing the intrusion that can go along with illness. Goffman (1963:28) argues that there is a perception that as long as they seem sympathetic, strangers feel able to approach a stigmatized person and express 'morbid curiosity' about their condition. As discussed in the previous chapter, Joy had reported several instances of intrusive questions regarding her decision to have a mastectomy. Similarly Gray et al (2000) found in interviews with men with prostate cancer that they decided how much information to reveal judged on the other person's right or need to know. Generally they did not talk about it because they believed it was nobody else's business.

Finally, whilst the response, 'I'm fine' is usually either a way of deflecting unwanted intrusive questions or hiding distress, in the current study Nina reported a different reason for saying it. In contrast to Joy, Nina who also had a mastectomy but no further treatment, told me that she answers 'I'm fine' even when she is actually feeling really good:

I know this sounds really daft, I don't know if anybody else has ever said this, even though you're positive inside you daren't be too positive cus of the knock-back..when people go 'are you alright?' and you say 'yes, fine thanks' you know, what more can you say? Cus you do feel like you want to say 'well actually I feel really great, I'm on top of the world!', but then you think 'oh I daren't say too much, if I get a knock back and then it's like why did I think I felt so good?' So inside I feel positive but I don't always say it, I just say I'm fine.

Nina seemed to be worrying that she may be 'tempting fate' by replying that she is feeling good. She is revealing her insecurity with her body by fearing a 'knock back' where the fact that she had been so positive would make it harder to deal with should she become ill again. It is further evidence of the way that some women struggle with the uncertainty about possible recurrence of cancer as was discussed in chapter 5.

It seems that self-censorship performs various purposes from protecting the self to protecting other people and that this continues even after treatment ends as will be seen in the following section.

Visibility

In the previous chapter I highlighted the way that women are encouraged to normalise their appearance after treatment for ESBC/DCIS through surgery or use of prostheses. Though the participants reported that this helped them to regain confidence socially, there were implications for relationships. Because of this lack of visibility due to the effort that most women had made in order to 'normalise' their appearance, after treatment had ended it was hard to tell what they had been through. This was the time that was identified by some of the participants as particularly difficult, such as Andrea, who had been through treatment for breast cancer twice:

Once you've had the treatment you begin to look normal again and then you..and that applies in work situations, family, friends, new friends, social situations, where people say 'how are you?' and you think, what bit am I gonna not say? So there's a lot of that, well there was for me, that balancing, and thinking 'what would be good for me? What would be good for them?' you know so that, that was a constant.

It seems that once her hair grew back, Andrea was no longer instantly recognizable as someone with cancer and was able to have some control over what information she chose to reveal and to whom, on the basis of what would be good for her as well as for other people. It was identified as one of the problems faced by women in the post-treatment period. Goffman (1963:57) argues that when 'differentness is not immediately apparent' decisions must be made to 'display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom how when and where'. Andrea likened it to her other point of difference, where she had to decide who to tell that she was a lesbian.

For example, she told me that when she was in the hospital a nurse had asked if she had grandchildren and she needed to consider whether it was worth going into detail about why she did not have any. Likewise, Stacey (1997:67), a lesbian who also had cancer, argues that 'passing is similarly a constant part of everyday life in relation to sexualities designated as deviant'. Stacey describes how deciding whether to 'come out' both in terms of sexuality and cancer status, was something she had to negotiate 'almost on a daily basis'. Stacey argues that her previous experiences of homophobia lent her a different lens with which to view cancer since both her status of lesbian and cancer patient were subject to cultural anxieties. Consequently both she and my participant Andrea could be described as doubly victimised by virtue of their two stigmatized identities.

Another participant, Phoebe, talked about the consequences of revealing her cancer status. She told me that she had been very open about her mastectomy and reconstruction at the time she was going through it, but now that she was 5 years post-treatment she felt that things had changed:

I think though the longer you go on you do get a bit blasé..you just come out with it as a matter of fact now and some people are really shocked. They don't know what to say and you don't realise, you think 'oh I wish I'd not told them actually. Why did I tell them? I didn't really need to tell them'.

Phoebe is illustrating the consequences of revealing an invisible stigma (Goffman, 1963) because it shocked people who had previously been unaware. It seems that with the passage of time, Phoebe had become less sensitive to other

people's reactions, forgetting the shock that her revelation would engender. As Hochschild (2003) argues, it suggests that women in particular feel the need to protect other people from being upset and to look after them. This is an aspect of being stigmatized that Goffman (1963:145) describes as feeling obliged to 'protect normals' by behaving appropriately. However, there seemed to also be consequences for behaving too normally, as Nina discovered in this conversation that she reported having with a work colleague:

She says 'you come in here dead happy, get on with your work and we have a laugh and' she says 'you never, I would never ever think that you've had cancer, that you've got-' and I think how would you look if you'd got cancer? Does it say on my head? I don't know, it's like anything isn't it? Any illness I think not necessarily cancer.

This reaction would be more understandable in the context of cancer treatment which often does leave visible traces, particularly hair loss. However Nina (who did not lose her hair) reportedly had this conversation after her treatment had ended when she had returned to work. This suggests that her colleague does not actually think that 'normal' returns in an uncomplicated way but recognizes that things will be inevitably and irrevocably changed. This reveals a particularly interesting contradiction in that some women report negative feelings around assumptions that they will return to normal, yet Nina in the above quote criticises someone for assuming that she should maintain some aspects of her illness role, or at least be 'changed' by her experiences. This highlights the difficulties faced by family and friends who have to negotiate the parameters of a 'new' relationship. They seem to be in a

double bind where they are unable to treat people as if they are still ill, but also unable to treat them as if they are 'better'. Nina's colleague's comments also suggest that there are implicit rules about how somebody who has had cancer (or indeed any illness) should behave which apparently Nina had failed to adhere to. Goffman (1963) argues that this is a pitfall of a stigmatized person who is trying to normalize their behaviour, citing the example of a blind man whose joke was met with silence and reflected 'the silence told me that I wasn't a man who should make jokes, not even good ones' (Chevigny, 1962:68 quoted in Goffman1963:145). In Nina's case, the stigma seemed to have stuck even after treatment had finished.

The previous examples have highlighted some of the difficulties that participants reported when recounting struggles with 'normals'. Consequently, many participants suggested that they could only really be honest with women who had been through a similar experience, and this will be discussed in the next section.

Other women with breast cancer

A common theme within the participants' narratives was that they valued the support of other women who had experienced breast cancer because they appeared to really understand what they were going through. Malaika, who lives alone, told me that she valued the practical help of a friend who had previously had breast cancer who, when she visited Malaika, said:

'Ok, what wants doing?' And I said 'everything's fine'.

'Do you want me to clean your bath?' And I looked at

her. She said 'come on' she said 'I've been there and I know one of the most awkward things to do on any given day is clean the bath!' she said 'and it's not probably something anybody's offered to do for you have they?' And it just brought tears to my eyes because it's that sort of thing that's really **really** coming from someone that understands..Cus you'd never ask anybody to clean your bath for you.[participant's emphasis]

Deborah Orr (2012) writing in *The Guardian* about her own experience of breast cancer, says that she found it annoying when people asked if there was anything they could do because that gave her an added burden of assigning a task to them. She said she much preferred an offer of a specific task. It seems that as a result of her own experience, Malaika's friend was able to discern the type of jobs that she would need help with which would be too embarrassing to ask for under normal circumstances. This type of support does not just refer to practical matters though. According to Bury (1991), a major aspect of support is the chance to confide in others. When the participants did not want to talk to family or friends because they might upset them, or because the family did not want to listen, then they turned to other women who had been through a similar experience. Wendy told me:

I do have a friend who had breast cancer and I found you do wheedle out those sorts of people and I mean I do remember when I found out, she was the first person I went to. I didn't want to talk to anybody else because they don't understand. You can't really understand. And we had a lot of cuddles me and her!

Like Wendy, most participants reported that they felt more able to be open and honest about their feelings when sharing them with another woman who had been through breast cancer. According to Frank (2002) the benefit of talking to other people who have known critical illness is that they treat each other with respect and affirm their experiences in contrast to 'normals' who often seem to deny them. He proposes that: 'human suffering becomes bearable when we share it. When we know that someone recognises our pain we can let go of it' (Frank, 2002:104). By drawing on the experience of her friend as someone who could empathise with her, Wendy is illustrating Bury's (1991) argument that people respond to illness by mobilising resources. Other participants described seeking out information from other women who had been treated for breast cancer, such as Maggie who told me:

I had a very good friend who had been through it and so she was one of the first people who I rang when I knew and she talked me through everything. And also my husband met somebody through his work who had been through it at exactly the same time the year before, even had the same surgeon. And I spoke to her and she was very very helpful, I talked to her a lot on the phone. Because it was so recent for her she could remember all the stages and what bits were difficult, what the pain was like and that kind of thing. And then I kept in touch with her for a bit afterwards and I still see her now and again. So I think that the support of other people that have been through it is helpful.

It seems that women who had been through treatment already were uniquely placed to offer reassurance and

guidance about what would happen when. This seemed to be a way of restoring a sense of order after the disruption caused by being diagnosed with breast cancer. Sometimes this had initiated friendship as Maggie described, but sometimes it was an already established friendship, as in Connie's case:

Dorothy and I were friends before but I can never, ever pay the debt that – [pause] Dorothy had had a mastectomy and there's no history of it in our family at all. And when she found out, I was in bits. And I went round and I spoke to her and she was absolutely marvellous. She actually took it stage by stage with me; this'll happen, that'll happen, you know, and it sort of registered the back of my mind and as things were happening it was like 'ooh yeah'. I was in bits. And one thing she did do, and I can never repay her for this, she said to me 'have you ever seen anybody that's had a mastectomy'? And I said 'no', I said, 'I've seen photographs that they show you' and she.. stripped off and not even her daughters had seen her, you know, stripped off. And that meant so much. It really did mean a lot. And I knew what it had taken once I had my operation; I knew what that had taken for her to do.

Connie said (twice) that she was 'in bits', reinforcing the view of breast cancer as traumatic because it can reveal the fragility of health and shatter people's assumptions of themselves as healthy (Janoff-Bulman, 1992), as previously discussed. With apparently nobody in her family to turn to, Connie's friend seemed to have helped her to regain some control over what was happening, not just by giving her information but also showing her post-mastectomy body which she had not even revealed to close family. This act of trust in

a potentially stigmatizing situation seems to have deepened the bond of friendship between the two women because Connie says she can 'never repay her for this'.

Many of the participants told me about how they had been contacted by other women who had experienced breast cancer offering their support. Sometimes it was someone they vaguely knew or a friend of a friend that came out of the woodwork. In this respect, women who worked outside the home seemed to have a larger network of people to draw upon, as demonstrated by Sophie's experience:

What happened was my line manager spread the word quite quickly and I got an email within the day from another member of staff who I'd worked with for about 18 months and I had no idea that she'd had a double mastectomy. I remember it to this day, she said 'really sorry to hear that but something you've got to know is that my experience is that after the initial diagnosis everything was astonishingly untraumatic'. And I remember those words. Those words went vroom! on my brain. And actually that's how it's been. And I think well if she can do it, and this is like 13 years on so things were a lot more barbaric in her day, so can I.

Sophie was unaware that her colleague had had both breasts removed and therefore seems to have successfully 'passed' as normal (Goffman, 1963:58). 'Passing' according to Goffman involves the management of discrediting (or stigmatizing) information about the self. Nevertheless, Sophie's colleague had apparently revealed her 'discreditable' status and risked being stigmatized, in order to offer support. Sophie seems to have taken solace in the fact that her colleague had survived

for 13 years, reasoning that 'if she can do it..so can I'. This support was not a one-way process however. There were many examples where my participants had used their experiences in an altruistic way as will be discussed in the following section.

Identifying with, and offering support to others

Bury (1991) argues that a concentration on negative aspects of the illness experience such as problems of managing illness, symptoms and stigma can ignore the ways that some people actually use their experience in a positive way. In the current study, participants reported that their experience had given them an insight into the realities of having breast cancer and some, such as Viv, reported that they were more sympathetic as a result:

People can't understand unless they've been through it. Cus I didn't understand cus I'd before I had it I had a colleague at work who had it and you just think 'oh, it's finished, just get on with it'. She always used to say 'oh I'll come out with you next week, if I'm still alive!' She was always saying 'if I'm still alive'. But she obviously felt like that didn't she? Bless her. I think everyone else thinks 'oh god. Get on with your life! Worse things happen!'

Viv highlighted the inappropriate responses to people who have survived breast cancer with a realisation of how she had been prior to her own illness. It seems that as a result of her own experience, Viv has realised how unhelpful her reaction to her colleague had been. She now appreciated that her colleague could not 'just get on with it' but that insight would

not have been possible if she had not been through a similar thing. Another example was provided by Wendy Y who worked as a nurse manager. She told me that her friend had died of breast cancer a few years before Wendy was diagnosed:

I'm sure I could have given my late friend more had I known a little bit more. Not beating myself up about it, I can't help that, but I could, I definitely could and I'll certainly you know be around for anyone else who ever needed any emotional support. And I think that's the biggest thing. All the physical stuff's out there for you but I think it's the emotional thing and it is, it's massively emotive.

Wendy is echoing a comment that came up in several interviews that the psychological aspects of the treatment for ESBC/DCIS were particularly difficult to deal with. As was mentioned in chapter 4, Connie told me 'breast cancer is 50% there [pointing to chest] and 50% there [pointing to head]' and June said, 'that's the biggest thing with women you know. You've got to control this [pointing to her head], not this' [pointing to her breast]. As a result of her own experiences, Wendy reported that she was aware that the best thing that she could do for other women with breast cancer would be to offer emotional support. Waxler-Morrison et al (1991) criticise the assumption that sick people are simply recipients of social support. Their interviews with 18 women who had survived breast cancer revealed many instances where they had offered help and advice to others and this interactive relationship was mutually beneficial. Similarly, the current study revealed many examples of participants electing to use their experience to help other women, the main one of course being their

willingness to take part in this research, as was discussed in chapter 3.

Although they could have used their recovered appearance to 'pass' as normal (Goffman, 1963), some had chosen to maintain their cancer identity for political purposes. For instance, Sam takes part in a cancer forum to try to improve treatment for cancer patients and is also a 'Macmillan voice' where she gives feedback on the charity's publications. She reasoned, 'you've got to use your experience for something haven't you?' Also, Connie told me how she had been proactive since her recovery:

The support group wasn't for me because I didn't want to sit and talk about chemotherapy and operations and ..all the rest of it. I wanted to do something positive you know that's why we tried to raise the money. And I think although you've just been hit with the hardest bullet of your life probably.. you need a positive, but that's my thing in life. You **can** get over it, you **can** you know whatever. I know not everybody does.

Raising money for the ward where she had been treated seemed to provide Connie with a sense of purpose, helping her to 'get over it'. It highlights the pedagogic value of trauma that can engender a sense of unification and lead to a community of women based on past trauma and ongoing vulnerability. Seale (2002) argues that based on his comparison of the representations of men and women undergoing cancer treatment, women are far more likely to use their experience for such altruistic purposes. The more positive outcomes are also highlighted by Joachim & Acorn (2000) in their review of research on illness experiences.

They criticise the tendency to concentrate on either stigma (the negative reactions of society) or normalization (positive reactions of individuals). They propose an integrated approach where people embrace their stigmatized identity to take political action. Joachim & Acorn (2000) argue that those who have a stigmatizing condition can be empowered by identifying with similar others, as Connie and other participants have done and that taking political action can mean that they are no longer in a victim role. Connie is also demonstrating Bury's (1991) observation that people often take positive action to counteract negative aspects of their experience and improve their quality of life. In the trauma literature, this response is known as 'post-traumatic growth' (Joseph & Linley, 2005). Frank (1995) describes all such examples of using illness experiences as 'quest narratives' which are defined by the belief that something good can result from their illness. Frank argues that in these cases, people embrace the experience and try to gain something from it, perhaps using it to help other people. It is one of the ways that people find meaning within their experience of illness which, according to Bury (1982), is a way of coping with biographical disruption.

Nevertheless, there are drawbacks to making assumptions about common experiences which will be discussed in the following section.

Problems of assuming everyone's the same

Although most women said they valued someone to talk to who had been through a similar experience, some participants

reported that they did not always find it helpful, for example Karen told me about her sister-in-law:

She's a nurse but she'd had this lump for over 6 months and she'd found it and was just too scared to do anything about it and then when she did do it had got so big that it's attached itself to her chest. So she's had an awful time. She had to have quite a lot of chemo beforehand and thankfully it did shrink during the second half of the treatment..But apparently she was bad all the way through chemotherapy and the way she talked to me, as though I was going to be exactly the same. I had to take it up with her. You know 'I hope you're getting plenty to eat' and thinking 'oh gosh I'm eating too much really' but she's very much..oh I was going to say wallowing in it but I shouldn't say that cus that's very derogatory but she is, well she's the victim I suppose. But for me it's no positiveness about anything and its all doom and gloom and its, it isn't really you know. You think that each step is one step forward and what is it doing? It's saving your bloody life for you hopefully!

Karen seemed to have resented the assumption that her experience would be the same as her sister-in-law and in her account she highlighted the differences between them. Unlike Karen, she had apparently delayed seeking treatment even though she is a nurse and presumably should have known the risks of doing so. This implied a moral judgment on her for leaving it so long that the cancer had worsened. Also this woman had lost her appetite during chemotherapy, whereas Karen felt that she was eating too much. Finally, Karen believed that her sister-in-law was 'wallowing' in it, had a

victim mentality and had 'no positiveness', whereas Karen took the view that even though the treatment was unpleasant, it was hopefully saving her life. Despite the similarities in their predicaments, Karen seemed to be constructing herself as different to her sister-in-law by pointing out the differences that she disapproved of in her behaviour. Just as participants reported that they resented the assumption that everyone is the same during treatment, there were also similar concerns after treatment. For example Martha said:

We've got a friend who is younger than I am and has had a mastectomy. And she's out campaigning for breast awareness and I just think 'oh shut up! not every cancer is like yours. And not everybody wants to talk about it all the time'.

Both Martha's friend and Karen's sister-in-law are good illustrations of Frank's (2002) argument that other people's stories are just that- they are unique to them. The point is that people have different experiences, they do not all respond in the same way, it could be better or worse. Frank (2002) argues that the main thing is for people to be free to experience in their own unique way without feeling bad for failing to adhere to some ideal norm of responding to cancer, be that in a positive or negative way. Martha's final comment 'not everybody wants to talk about it all the time' was perhaps the sentiment that influenced some of the participants' reactions to breast cancer support groups that they encountered, as I will now discuss.

Breast cancer support groups

Of my 24 participants, only Phoebe reported that she regularly attends support group meetings. She told me that she was recommended to go by a counsellor during her treatment for depression and said:

You don't really get, if they weren't doing the support group you wouldn't get any emotional support I don't- where else would you get any emotional support? I mean you can go to your doctors and to a counsellor and everything but unless, when you're talking to a group of people that have all had the same thing, you can sort of say anything can't you? and you know that people understand. That's the only real support, I feel.

Phoebe reported that she found it particularly helpful to compare experiences and be able to help somebody else in the process:

At the time there was somebody there, I must have gone when I'd just had my implant put in, she'd still got her tissue expander in so I could say 'did you feel like this?' so .. I could help somebody else in a way. So that did help a lot actually because you suddenly think – cus you can't talk to – some things you can't say to people that have never had it cus they're not gonna understand, you just wouldn't want to..but if it's people that have had it, even if they're all complete strangers, people will come up to you and say 'oh have you had a mastectomy?' 'which one is it?' 'what have you had?' But you wouldn't say that to people in the street would you?
[laughs]

For Phoebe, the support group seemed to have provided a space where social niceties could be ignored to the extent

where personal information could be sought and given, in the secure environment of people who were in a similar situation. This is described by Goffman (1963:137) as an 'in-group alignment'. Interestingly, in this situation the straight questions regarding treatment choices seemed to be welcomed, in contrast to the earlier cited examples where such questions were considered to be intrusive. The difference was that all the women were in a similar situation and equally vulnerable. This was also the case in Gray et al's (2000) study of men with prostate cancer who reported that even though they generally did not like to discuss it because they felt that it was nobody else's business, they were willing to do so with other men in a similar situation.

Recognising the potential value of peer support, medical professionals often call upon a volunteer from the group to talk to women after diagnosis but this intervention seemed to provoke mixed responses from my participants. Some women such as Joy reported that they welcomed the reassurance of seeing and hearing from a woman who had been through treatment and survived and said she 'felt better' after their chat. Others however found the presence of a stranger, no matter how well intentioned, to be too much, too soon. Malaika described her experience:

We went and sat down in a little room where they said they would bring me some information and sit and wait there and talk to somebody. And a really lovely lady came in and gave me a leaflet for the support group and said "you're just in time for the Christmas party!" And I remember looking at her and thinking "she really didn't just say that!" And when she walked out I glared..and I said to my mum "that is one club I don't wanna be a

member of," you know, "why would I want to be a member of that club?" She was just doing her best. I do believe it was just wrong words, wrong thing to say.

From Malaika's description, it seems that the woman had become blasé and failed to consider the shock that Malaika must have been feeling having just received her diagnosis. On the whole, my participants rejected the breast cancer support group saying that it was alright for other women but that they felt it was not for them. Partly this seemed to be because participants were trying to distance themselves from the cancer identity. Maggie told me:

I never felt like joining any of the support groups. Because I didn't particularly want to, I kind of wanted to get it over with and move on with my life and because I suppose I was one of the lucky ones, it hadn't spread, I sort of thought I don't particularly want to spend my time discussing it with others.

Maggie seemed to be implying that the support group is primarily for women suffering from ongoing cancer whereas she seemed to no longer identify herself in this way. This is further evidence of the perceived gulf between my participants who had ESBC/DCIS and other women with more advanced cancers. Maggie is distancing herself from the other women because her cancer had not spread which she felt 'lucky' about. As she alludes to, one of the problems with support groups (both actual groups and on-line support forums) is that women with early-stage and secondary cancer share the same space and consequently, encounter the stories of other women with poorer prognoses than theirs. As Bury (1991) points out, comparison to others in a similar situation can cause worry as

well as comfort. This was illustrated by two of my participants who described their experiences of going to (different) support group meetings when they had first started treatment and were feeling particularly vulnerable. This is how Sam described hers:

I did go to a support group but I didn't like that, it was awful. I went with a friend who's a little bit older than me so everybody thought it was her so they didn't even speak to me and they were all round her. And she's fine, got a great pair of knockers! And the first thing [the chairperson] said was 'welcome ladies we're going to start this week's meeting with a two minute silence to remember ...' reeled off 5 or 6 names, these friends who are no longer with us. I thought 'I've come to get a bit of support and within half an hour of being here I feel like absolute shit and I want to go home!' So I didn't go back there.

Sam seems to contrast herself with her friend who although older than Sam, is described as 'fine' with 'a great pair of knockers' – a humorous and slightly derogatory term which seems oddly out of place in this context but suggests the value of breasts in Sam's view, possibly because she would like to be described similarly. Not only was Sam apparently mistaken for her friend's carer due to her young age, it seems that attending the meeting had the opposite effect to the reassurance she was seeking. Similarly, Barbara D told me that she had tried support groups but found the expression of condolences for deceased members, whilst understandable, too much to bear. It seems that for Sam and Barbara, support groups served to reinforce the idea that breast cancer can be

a terminal illness¹¹. Nina described why she had declined the help of the support group:

I was just worried that -not everybody's lucky are they? [pause] and I don't think I could be around people that weren't [pause] lucky [starts to cry] and it does make me feel guilty, I felt really, really guilty. I still do in a way

D guilty about what?

F cus like some people have to go through chemo and everything and [crying] I haven't. And people do think, cus you haven't had chemo it's not any worse than somebody else. They think it's not as. Well they just say 'well you're alright then aren't you?' but they don't realise what you have to go through.

Nina is pointing to the reactions of other people which may have been real or imagined. However, Peters-Golden (1982) found in her interviews that non-cancer patients, particularly men, assumed that breast cancer is not as serious as other cancers. They failed to perceive the concerns of breast cancer patients beyond dealing with the loss of the breasts. Problems of adjustment after the end of treatment such as fear of recurrence and, as Nina reports, guilt that she had not suffered as badly as other women, were not acknowledged.

Survivor guilt

¹¹ These findings contradict those of Sandaunet's (2008) study of Norwegian women's (non)participation in an online support group. Some of her participants reported that difficult topics such as meaningless and depression were avoided in favour of 'socially desirable responses'. Sandaunet (2008:1640) argues that women did not participate in the group because they perceived it to be 'too successful' and felt unable to be similarly upbeat.

It seems that Nina felt guilty because she had not suffered as much as other women with breast cancer and this was a common reaction amongst other participants, no matter what treatment they had had. This was compounded when participants were aware of other women who had died, where they seemed to be suffering guilt for having survived, as illustrated by Ruth:

I remember the worst time of all I was at a supermarket- oh hang on! [starts to cry] and a chap I know came up and his daughter had died of cancer. Oh! I thought, 'I wish I'd died', I felt terrible [crying] I couldn't face myself at that moment. Remembering that, it just makes me cry. Thinking about this poor chap's daughter, I sort of started to feel responsible for being alive and somebody else being dead.

Ruth is displaying survivor guilt, which is a well documented phenomenon in families with the condition Huntington's disease. For example, Tibben et al (1992) found that even though they expected people to be happy to learn that they were not carriers of the Huntington's disease gene, they suffered survivor guilt and emotional numbness in 8 out of 9 cases. Similarly, it seems that Ruth is still feeling guilty about surviving because this was the only time in the interview that she cried. She went on:

It kills people and you still somehow feel responsible for that fact. I still feel it now when I find out people who are younger than me have died, you feel terrible about it. Instead of being the lucky ones you somehow, well we are the lucky ones but you don't feel lucky do you? you feel. Well I suppose mostly you do feel lucky to have

survived it. There's an awful lot of very well meaning sort of positivity about it all but it doesn't really deal with what you're going through does it?

Ruth is expressing a tension between how she feels and what she believes to be the appropriate response to her survival. Ruth was expressing ambivalence, feeling 'lucky' in an objective sense to have survived but also feeling guilty that she is still alive when others are not, particularly when those who die are younger than she is. This is a common reaction amongst trauma survivors, and a symptom of post-traumatic shock disorder (PTSD) (www.mental-health-today.com/ptsd/dsm.htm accessed 2.4.12) Clearly Ruth has not been 'lucky' because she has had a double mastectomy, chemotherapy and radiotherapy followed by a bout of depression. Although Ruth acknowledged that there is an expectation that she should be projecting 'positivity', her feelings were apparently much more complex. It seems that rather than being true to herself, she is trying to conform to the expectation of positivity, a view that is informed by the public perception of breast cancer discussed earlier.

Chapter summary

This chapter has continued the theme of biographical disruption by looking at the impact on interpersonal relationships of a diagnosis and treatment of ESBC/DCIS and beyond into the post-treatment period. It began by considering the disruption to women's domestic and maternal roles as a result of participants' inability to carry out some of their tasks, but also demonstrated how firmly they clung on to their caring role. This discussion also encompassed the

implications of handing over responsibility to other people and subsequently trying to regain control after treatment ended. A limitation of the current research is that I only have the participants' perspectives on their relationships. Studies from the perspective of carers e.g. Ussher et al (2011) or other family members e.g. Davey et al (2005), reveal a different side of the story but unfortunately, such considerations were beyond the scope of the present study.

I also considered the role of social support and the impact upon my participants of the coinciding withdrawal of both practical and emotional support at the end of treatment. There were also instances where appropriate social support failed to materialise and possible reasons for this were considered with reference to Goffman's (1963) theory of stigma.

In the previous chapter I discussed the push for participants to normalise their appearance. This theme has been carried forward to the current chapter to reflect on the implications of this lack of visibility such as the assumption that looking normal means that women have resumed their pre-cancer state. The impetus to be normal for others and the public notion of positivity was discussed with reference to Hochschild's (2003) concept of emotional labour. This suggested the particularly gendered aspects of the participants' relationships and in particular the way they censored themselves in terms of the way they spoke to other people. Reasons included protecting themselves from intrusive questions and also protecting others. However, the costs of self-censorship were also evident in some of the participants' reactions which at its worst included depression.

One group of people that the participants reported being able to express themselves fully was with other women with breast cancer. Sometimes these were friends or family members, but there were also examples of unsolicited support from relative strangers. I then explored the ways that participants reported that they had reached out to other women going through breast cancer, having learned from their own experiences of the benefits of providing an empathetic understanding of the complexities involved in negotiating a 'new normal'. However these encounters were not always beneficial which highlighted the danger of assuming that all experiences are the same. Participants pointed out differences between them and people they came into contact with, particularly in hospital or support group settings. This seems to have generated a variety of responses from thankfulness that they are 'lucky' in comparison, to feelings of survivor guilt. Whilst being grateful to be alive, several participants reported feeling guilty that they had lived whilst others had died and some expressed guilt about not having suffered to the same degree as other women with breast cancer. This seems to have impacted on the support that the participants felt able to access.

The representations of breast cancer and its treatment in contemporary British society highlight the conflicting types of discourse which abound regarding this sensitive and traumatic subject. The findings suggest that cancer in general, and breast cancer in particular, is still difficult to discuss and represent. There remain legacies of a taboo surrounding both cancer as a potentially fatal illness and breasts with their symbolic associations with sex and nurturing. On the other hand, media portrayals of breast cancer survivors and publicity campaigns used by breast cancer charities often

present a more positive image which can be hard to reconcile with the realities of living with and beyond a life-threatening disease and its treatments. Clearly there are mixed messages in the various portrayals of breast cancer which women who experience ESBC/DCIS must navigate in order to establish a 'new normal' in the wake of their biographical disruption.

Chapter 8: Conclusions and reflections

Introduction

I began this thesis by describing my journey to this point in my academic career and the life events that led to my choice of topic. In the introduction I posed a series of questions in order to explore the experiences of women who, like me, had been treated for early stage breast cancer (ESBC) or ductal carcinoma in situ (DCIS). As the study progressed, the focus shifted from experiences of diagnosis and treatment to the period after intensive treatment had finished. This was the point at which I interviewed all but one of my participants and it seemed that this period presented particular challenges which warranted further investigation. The post treatment period is important to study because the development of ever more efficient detection and treatment means that there are increasing numbers of women surviving ESBC/DCIS.

Nevertheless, it was necessary to begin with a discussion of how participants experienced diagnosis as often this was the first time that they had been seriously ill and sometimes represented their first long-term encounter with the medical system. In chapter 4 I described Parson's (1951) sick role theory which sees illness as a social role and encompasses both rights and responsibilities. However, Parson's theory falls short of describing the experiences of long-term conditions, therefore Bury's (1982) theory of illness as a biographical disruption (detailed in chapter 2) was used as the theoretical framework throughout the thesis. This was

extended to consider the transition not only from assumed health to the sick role but also to argue that the end of intensive treatment can be experienced as a further biographical disruption.

Because the majority of my sample had completed treatment at least six months prior to being interviewed, some participants reported that this was the first time that they had the opportunity to reflect on their experience of having had a life-threatening illness. It seemed that some participants were in a state of limbo; no longer in the 'sick role' (Parsons 1951), but also not feeling able to describe themselves as healthy. In chapter 5 I described this period of transition as liminality and argued that for some women this would be their 'new normal' (Mukherjee, 2011b). The final data chapters were dedicated to a discussion of what living with their new normal entailed firstly in terms of bodily changes and secondly for interpersonal relationships.

In chapter 3 I discussed how my own experience of treatment for breast cancer has brought a unique perspective to this study, as well as aiding a deep understanding and empathy. However, this was also risky in terms of my own emotions. For example, whenever I see the widowers of my two friends who died of secondary breast cancer shortly after my treatment ended, I want to apologise to them for being alive when their wives are dead, even though I know this is illogical. Similar responses of 'survivor guilt' were discussed in chapter 7. My own response to these feelings of guilt is to do this research, where I hope to give voice to the many women who have been treated for breast cancer, whether they are still with us or not. In addition, my strong involvement with the participants' stories meant that I had to beware of accepting

their accounts unquestioningly. With this in mind, I acknowledge that a limitation of this study is that the analysis presented is just one of many possibilities; other researchers may have emphasised different aspects, or chosen to focus on other areas for analysis (McParland et al, 2010).

As a result of analysing the responses of my participants over the previous four chapters, I have reached several conclusions which all relate to the main research question: 'What is the 'new normal' for women who have finished treatment for ESBC or DCIS?' These will be drawn together in this concluding chapter in a summary of the research findings. In addition, I will indicate the limitations of the current study and highlight areas that merit further investigation. Conclusions 1-4 will address the research questions posed in chapter 1 and I then go on to discuss further conclusions that have arisen through analysis of the data.

Conclusion 1: ESBC/DCIS does not always result in biographical disruption.

This addresses the research question: 'How do narratives reveal the ways that women make sense of the biographical disruption caused by breast cancer?' As was detailed in chapter 3, the narrative approach was used in this study in order to explore the way that women made sense of the biographical disruption caused by the experience of ESBC/DCIS. However this approach also helped me to position the breast cancer experience within the context of participants' lives. This was important when considering why the diagnosis of a potentially fatal illness seemed to be more disruptive to some women than to others. The concept of

illness as a biographical disruption assumes that diagnosis comes out of the blue and although this was true in the majority of cases, there were exceptions. For example in chapter 4 I described how June reported that her family history of breast cancer meant that she was actually relieved to be diagnosed because it eased her guilt about passing the susceptibility to her daughters. In June's case, ESBC/DCIS was not experienced as a biographical disruption but perhaps a biographical continuity (Williams, 2000) as explained in chapter 4.

Not only prior experience of illness, but previous traumatic experiences also seemed to have lessened the impact of diagnosis. This was seen in Nina's story of her wrongful arrest (described in chapter 5) which she felt to be worse in terms of disruption to her self confidence than changes to her body. In Nina's case, biographical disruption originated prior to diagnosis and was still continuing when I interviewed her four years later.

In chapter 5 I described how Nina was one of many participants who expressed a feeling of being in limbo. This was described as liminality, a term adopted from anthropology which is defined by Turner (1969:95) as 'neither here nor there' because participants are 'betwixt and between' states of health and illness. Previous research has used the concepts of biographical disruption and liminality to study experiences of prostate cancer, but I believe that the current research is the first to combine them in a study of a cancer that mainly affects women. It therefore presented a unique opportunity to consider gendered aspects of the experience. I will return to this point in conclusion 4.

Conclusion 2: The end of intensive treatment can also be experienced as disruptive.

The question posed in the introduction was 'how do women experience the end of treatment?' The findings suggest that some participants had become accustomed to the 'sick role' (Parsons, 1951) and therefore the transition from the treatment period to a resumption of 'normal' life was also experienced as disruptive. Delayed reactions were often reported to have occurred once the intensive treatment was over and some semblance of normality had returned; when for example women no longer had to attend regular hospital appointments and many had returned to work. Consequently, at the time that they were interviewed some participants were only just beginning to deal with the shock of what they had been through because the rapidity of treatments had left little time for reflection. In the post-treatment period when most participants were interviewed they were in no immediate danger of dying of cancer, nevertheless they were displaying symptoms of trauma. In some cases these feelings were hard to convey, perhaps because of an implicit expectation that they should be happy to be alive and should put their trauma behind them and get back to 'normal'. This thesis has argued that for some women, a return to 'normal' was not possible, therefore they were living with a 'new normal' (Mukherjee, 2011b). What this meant in terms of their bodies and relationships was discussed in chapters 6 and 7. Therefore Bury's concept of biographical disruption was extended to the disruption caused by cessation of intensive treatment.

Conclusion 3: The post-treatment period can present further challenges to relationships.

The research question posed in chapter 1 was: 'What are women's experiences of relationships during and after treatment for ESBC/DCIS?' In contrast to many studies of social support which concentrate on the time when women are undergoing treatment, the current study was interested in the post-treatment period. Chapter 7 described how, in some cases, participants reported feeling that they had changed as a result of their experience whilst people around them had not.

In the narratives, participants often contradicted themselves. On the one hand they reported feeling resentful about requests for intimate details of their treatment that they found intrusive. In such cases they reported that their response was 'I'm fine', no matter how they were actually feeling. On the other hand, they sometimes complained that other people had stopped asking how they were, which they attributed to an assumption that everything was 'back to normal', although that was not how they felt. Participants expressed a need to talk about their experiences but this needed to be on their terms. It seemed important to be able to control what information was given to whom.

It seems that part of the 'new normal' involves renegotiating relationships that have been disrupted by the experience of ESBC/DCIS. Further research is needed to investigate the contradiction that some women report negative feelings around assumptions that they will return to normal yet others criticise those who assume they should maintain some aspects of their illness role. It highlights the difficulties faced by family

and friends who have to negotiate the parameters of a 'new' relationship. It seems that adjustments have to be made not only by the women who are going through the experience but also family members and friends who could benefit from some guidance or information as at the moment they may struggle to get the right balance. This would add to the body of knowledge surrounding the long-term implications on relationships following successful treatment of breast cancer; a growing need in view of the increased numbers of survivors in the UK.

Conclusion 4: The experience of ESBC/DCIS presents an opportunity to explore gendered aspects of biographical disruption.

In chapters 6 and 7 I discussed how the data revealed evidence of the particularly gendered nature of biographical disruption which is not so apparent when studying mixed cancer populations. This was in response to the research question 'What happens to a woman's identity when norms of femininity are disrupted by breast cancer and its treatments? How do women experience a 'new normal' body?'

In chapter 6 I discussed the ways that participants' described the impact of treatment upon their bodies. Because breasts are a defining aspect of womanhood, this presented particularly gendered challenges in respect of their self-confidence, sense of femininity, and intimate relationships. In some cases it seemed to threaten their very identity. Consequently a return to 'normal' became problematic and instead participants described living with their 'new normal'

bodies and what this entailed. Many studies of body image in women with breast cancer are conducted within a relatively short time following their diagnosis and treatment. However, the current research suggests that feelings change over time and that the full implications of living with a post-operative body are not felt until the initial shock has worn off.

Participants reported that when they were first diagnosed their feelings had concentrated on survival at any cost; therefore emotional attachment to the breast was minimized. However, the post treatment period revealed the consequences of the decisions that they had made. This study involved long-term survivors of ESBC/DCIS and therefore provides new insights into the embodied experiences of women in the years following treatment.

Data revealed that women's bodies were experienced as belonging not just to the women themselves but also other people, particularly their intimate partners. In chapter 6 I described how some narratives revealed how women's bodies are subject to public scrutiny. As was described in the case of Joy women reported blatant questions about the effect of their surgery on their sex life and expectations on behalf of friends and family that they would have reconstructive surgery for the sake of male partners. In addition, some participants implicitly referred to heteronormative assumptions made by the medical community which made reconstructive surgery mandatory. This aspect of the gendered nature of breast cancer was particularly highlighted by Andrea who was the only participant who identified as lesbian. Echoing feminist criticism of breast cancer treatment (Wilkinson & Kitzinger, 1993), Andrea was keen to highlight the assumptions of heterosexuality that were made during her treatment, pointing

out how it is commonplace to ask about a male partner's reactions to surgery. Andrea was perhaps more alert to these implicit assumptions than the participants who were actually in heterosexual relationships.

In chapter 7 I discussed gendered aspects of biographical disruption in respect of relationships such as domestic roles, particularly motherhood. It seems that the ongoing responsibilities of caring for other family members meant that they tried to carry on with these even when they were ill and undergoing treatment. It therefore presented women with a chance to retain elements of their pre-cancer identity and therefore could be described as biographical continuity (Williams, 2000). However, an important limitation of the current study is that it did not feature any participants who reported that their chances of motherhood were disrupted by treatments for ESBC/DCIS.

This brings me to one of the limitations of the current research which is the lack of diversity in the sample. As with most qualitative studies, this study was limited by the relatively small sample that I was able to access and interview within the time constraints of the PhD process. But also, as I discussed previously, participants were self-selected and although there was a good range of ages, unfortunately there was little diversity in terms of sexuality or ethnicity. Therefore a recommendation for future research would be the inclusion of a more diverse sample. This would perhaps highlight the differences in women's feelings about the impact of surgery on their body and relationships and challenge assumptions of homogenous reactions to mastectomy.

In addition, a longitudinal study could offer new insights into what it means for women to live with a 'new normal'. This is based on an observation I made when, 18 months after I interviewed her, one of my research participants (Malaika) invited me to a fund-raising event that she had organised for a breast cancer research charity. At the time of the interview she reported that she was newly single and was waiting for further reconstructive surgery. Malaika told me that she has now had the surgery and showed me her flat stomach and the scar along her waistline. I would love to hear about Malaika's feelings about her reconstruction and to find out whether she is now in a relationship. Also, this is an extract from an e-mail I received from another participant, Karen, whom I interviewed prior to her final chemotherapy session:

'Things are going well this side with chemo long past me (last one June) and now have thick, previously fine, head of hair. Slowly building up workload and trying to establish a new normal.' (e-mail 2/11/2011)

These two examples highlight the usefulness of re-interviewing some or all of the participants because all I can present here is a tiny snapshot of a few hours spent in their company and, as the previous two examples indicate, so much can change. A comparison of their comments in each interview may reveal if and how feelings towards their body and their relationships alter over time. This would add to the body of knowledge surrounding the post-treatment period which is necessary in view of the growing population of people surviving cancer.

I now turn my attention to additional conclusions that arose through analysis of the data which relate to the gendered

experience of ESBC/DCIS but do not directly address the originally stated research questions.

Conclusion 5: There are public perceptions of 'good' and 'bad' reasons for having breast surgery.

In chapter 6 I described how this research coincided with controversy over potentially harmful breast implants. A French firm had been using industrial grade silicone and there was a fear that if they ruptured, it could be damaging to women's health. There ensued a public outcry in the UK about women who had paid to have breast implants but were unable to have them removed by the private healthcare provider and thus costs fell to the NHS. Since these women were not currently sick, and since they had not undergone their initial surgery for health reasons, some commentators argued that the taxpayer should not be responsible for bearing this cost through the NHS. This revealed an interesting paradox. Women who had paid to have potentially harmful PIP implants were demonized for having breast enhancing surgery because it was perceived as vanity. At the same time some of my participants were reporting that they had felt pressurised to have reconstructive surgery and sometimes surgery to the healthy breast to 'even them up' (discussed in chapter 6). So, on one hand the societal message seems to be that breasts are important to women's self-image, confidence and relationships and therefore women with cancer should be offered reconstructive surgery. This highlights the heteronormative expectations and policing role that the medical community plays in this regard as previously stated. On the other hand, having surgery to the

breasts for any reason other than to remove cancer is seen as an unnecessary display of vanity. Furthermore, some participants reported that they felt they were expected to be grateful for their 'free boob job', despite the surgery being out of necessity.

Further research is merited in order to compare the experiences of these two groups of women in the light of this controversy.

Conclusion 6: The centrality of hair loss to the gendered nature of breast cancer

Not only does treatment for ESBC/DCIS involve surgery to the breasts but those who have chemotherapy also generally suffer hair loss. As argued in chapter 4, hair is a major factor in women's identities, an idea that is reinforced in popular culture. For the majority of participants who lost their hair, this was a more immediate and visible sign of illness and was experienced as disruptive to their identity, particularly their sense of femininity, as well as symbolising their entry into the 'sick role'. However, also in chapter 4, I described how for some participants, the fact that they did not lose their hair seems to have compounded their feelings of guilt because they had not suffered to the same degree as other women. I gave the example of Malaika who reported that she considered a woman who had lost her hair to be worse off than she was, because she had 'only' lost her breast.

In chapter 2 I described how stigma is associated with failure to comply with norms of appearance (Goffman, 1963). An unexpected finding of this research was that participants also

reported stigmatization due to failure to comply with the norms of the sick role (Parsons, 1951). Parsons argued that the rights to special consideration and freedom from responsibilities are conditional on looking and behaving in a way that is appropriate for someone who is ill. Because breasts are not visible in everyday situations there was no evidence of surgery available to non-intimate acquaintances; therefore hair loss was the most visible sign of cancer treatment. In one extreme case discussed in chapter 7, Phoebe reported that she was bullied upon her return to work because although she was medically well enough to return to work, her surgery prevented her from performing the full range of duties. Apparently, some colleagues were not prepared to cut her any slack due to a lack of obvious symptoms. Phoebe reflected that perhaps she would have been treated with more compassion and tolerance if the effects of her treatment were more visible and in particular, if she had lost her hair. Therefore, in this instance, it was not the fact that Phoebe looked abnormal that led to her stigmatization but that she was not conforming to the expectations of the sick role, and specifically to facets of appearance associated with cancer treatment. It seems that successful concealment of stigma can be problematic because people are expected to be entirely 'normal' even if they do not feel it. Furthermore, visible stigma perhaps serves a purpose by highlighting that a person cannot be expected to behave 'normally' in all aspects. Therefore this research has revealed an unexpected consequence of normalization in that patient benefits and rights are only afforded to those who look like patients. Further research is merited in order to explore the experiences of women who do not lose their hair when going through treatment for ESBC/DCIS.

Conclusion 7: The experiences of women with DCIS merit further investigation.

When I prepared the press release to recruit participants (see chapter 3), I asked for women who had been treated for DCIS as well as ESBC to contact me. This was primarily to differentiate women with these conditions from those with secondary cancer, metastases, where the cancer cells which originated in the breast had spread to other parts of the body and where recovery was not a possibility. However, the inclusion of DCIS not only attracted some of the participants who specifically wanted to talk about DCIS, but also led to some interesting data. Although it does not fit the usual definition of illness, being diagnosed with DCIS instantly places patients into the sick role. They have the disruption of having to attend medical appointments as well as having to decide whether to have their breast removed even though there is no certainty that their condition would ever be life-threatening. This highlights how the 'sick role' can be as much about the social aspects of being ill as actual symptoms.

Prior to doing this research I had assumed that the experiences of women with ESBC and DCIS would be similar, however the findings suggest otherwise. Despite the differences between breast cancer and DCIS, there are relatively few studies exploring the psychosocial aspects of women's experiences of DCIS specifically (Kennedy et al, 2008, 2012). In chapter 5 I described how the participants who had been treated for DCIS revealed complex feelings about their treatment. For example some revealed their confusion at

being told that it was non-invasive yet required urgent treatment.

The fact that DCIS entailed removal of part or the whole of the breast also seemed to be difficult to reconcile when it was not deemed to be life-threatening in the same way as ESBC. These feelings are reinforced by media reports based on research which cast doubt on the necessity for DCIS to be treated so radically when there is a possibility it may go no further (McPherson, 2010). Additionally, participants with DCIS did not require chemotherapy and that led to an unexpected reaction amongst them. Rather than just being pleased that they did not have to have chemotherapy and all the side effects that would entail, as mentioned previously, some participants expressed guilt that they had not suffered to the same extent as other women with more serious diagnoses. Some women displayed these emotions once they found out about my treatment. For example Wendy S. who trivialized her own surgery and radiotherapy saying that in comparison to me, she had had 'nothing'. The findings of this study suggest that there is a need for better information and support for women undergoing treatment for DCIS to help them to reconcile these mixed feelings.

Conclusion 8: It can be problematic for women with ESBC/DCIS to share the same sources of support with women with secondary cancers.

One of the more positive aspects of their experiences reported by the majority of the participants was the close connection that they felt with other women who had also been treated for ESBC/DCIS. There were frequent references to the support

they had received from friends and even strangers who had been through a similar situation. Some participants reported that such women were the only people that they felt were able to understand what they were going through and generally they appreciated the practical and emotional support that they could offer. However, this was not always the case, as was discussed in chapter 7.

My findings suggest that when the participants sought peer support, either face-to face or online, they were sometimes put off because they encountered stories of women with a worse prognosis. This sometimes made them feel guilty about surviving when others did not, and sometimes added to their anxiety about the possibility of recurrence. Consequently, instead of reassurance and comfort, breast cancer support networks often unwittingly reinforced the women's fears.

Further research exploring women's emotional needs could help to find a solution so that women with ESBC/DCIS can access appropriate support.

Chapter summary

In this concluding chapter I have outlined the main findings of this study which was based on the narratives of 24 women who had been treated for ESBC or DCIS. By considering the data through a feminist lens, I have endeavoured to explain the unique challenges faced by this group of women. They have survived a life-threatening illness yet are living with its consequences both in terms of bodily changes and relationships, which seem to be intricately connected. Hair and breasts are central to women's appearance and identity, each of which can be affected by treatments for ESBC/DCIS.

Therefore exploring the consequences of breast surgery in particular has necessarily highlighted gendered aspects of biographical disruption and liminality. This is a major contribution to the sociology of health and illness literature.

The narrative approach has revealed the complexities involved where on the one hand participants reported being glad to have survived yet were coming to terms with the enormity of what they had been through. This coincided with the loss of both medical and social support, leaving many participants to deal with these complex and contradictory feelings seemingly isolated from the support they had benefitted from during the period of intensive treatment. At the same time there seems to be various expectations associated with survivorship which form public narratives surrounding breast cancer, such as an emphasis on positivity, which participants struggled to reconcile with their actual feelings.

In addition to the original research questions, data revealed important issues affecting women undergoing treatment for ESBC/DCIS which differentiated them from women with secondary breast cancer and highlighted potential areas for further research.

Focussing on the post-treatment period emphasised the potential trauma of returning to the normal, the everyday, and the routine that people are expected to do seamlessly once the 'sick role' has ended. Instead, this study has shown how this transition is challenging not just for the women themselves but also for their families and how everything has changed forever even as everything remains the same. This constitutes what I have come to call a 'new normal' and is a unique contribution of this thesis.

Concluding reflection

During the thesis I have revealed my own search for meaning in this experience. All along I had wanted something good to come out of what was a traumatic event for me and my family and friends. I did not want it to be for nothing. I had turned to the familiar when I was ill by studying towards my MA with the Open University. Thankfully I then was successful in gaining a funded place at the University of Nottingham to pursue my studies. In the process it has been a privilege for me to share the narratives of the 24 women who were kind enough to trust me with their stories. I hope that the women that I interviewed found participating in my study a positive experience and that I have not misrepresented them in my analysis of their narratives. Hopefully the conclusions I have reached, along with the suggestions for further research, can go some way to increasing our understanding of what constitutes 'normal' for women who have been treated for ESBC or DCIS.

When I met with Nina 18 months after our interview, she asked me to write a book 'for someone like her' that said 'it's ok to feel like this'. And that is what I would like to think I have done for my participants – I have given them space to express the complex, contradictory emotions that they had been storing up and as a consequence given them permission 'to feel like this'. But I did not write the thesis to sit on a shelf; I want my participants' experiences to speak to other women going through similar experiences. So, just as Frank (1995) promised in relation to his research, I will write the articles and raise these issues to represent these women as best I can to let their voices be heard. And then I will have fulfilled my own quest narrative. For me, this has become my 'new normal'. 21/11/2012

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Appendix A

Information for Participants

Project title: Women's experiences of a diagnosis and treatment for breast cancer

1. This study is being carried out by Diane Trusson as part of a PhD in the School of Sociology at the University of Nottingham
2. This is a study of how women experience a diagnosis and treatment for breast cancer and how they adapt to life after treatment has finished. This may help identify ways that professional intervention can be planned to assist the process.
3. Women who have had treatment for breast cancer will be interviewed. The aim is to enable women to talk about their experiences in their own words.
4. Evidence suggests that it may be beneficial for people to talk about traumatic experiences with an empathetic listener.
5. There is a possible risk of becoming upset but hopefully this will be outweighed by the benefits. However, support is available at <http://www.macmillan.org.uk/> or the **Macmillan Support Line** (free) **0808 808 00 00 (Mon to Fri, 9am - 8pm) or Breast Cancer Care** <http://www.breastcancercare.org.uk/> **Free Helpline - 0808 800 6000** Monday - Friday, 9am - 5pm, Saturday, 9am - 2pm
6. There are no costs or inducements to taking part in the research.
7. Participation in this research project is voluntary and you may withdraw at any stage, including after the interview has taken place, without giving any reasons.
8. Your name and any identifying features in the information will be removed as soon as possible.
9. Anonymous quotes may be included in the written report.

Contact details

Researcher: Diane Trusson, Tel: 0115 9515235, email: lqxdskt@nottingham.ac.uk or write to address below

Main Supervisor: Professor Stephen Joseph, 0115 9515410, stephen.joseph@nottingham.ac.uk or write to address below

Complaint procedure

If you wish to complain about the way in which the research is being conducted or have any concerns about the research then in the first instance please contact Professor Stephen Joseph. If this does not resolve the matter to your satisfaction then please contact the School's Research Ethics Officer, Professor Bruce Stafford (tel. 0115 846 7439, email bruce.stafford@nottingham.ac.uk).



Appendix B.

School of Sociology and Social Policy
University of Nottingham

Participant Consent Form

Project title: **Women's experiences of a diagnosis and treatment for breast cancer**

In signing this consent form I confirm that:

| | | |
|--|-----|----|
| I have read the Participant Information Sheet and the nature and purpose of the research project has been explained to me. | Yes | No |
| I have had the opportunity to ask questions. | Yes | No |
| I understand the purpose of the research project and my involvement in it. | Yes | No |
| I understand that my participation is voluntary and I may withdraw from the research project at any stage, without having to give any reason and withdrawing will not penalise or disadvantaged me in any way. | Yes | No |
| I understand that while information gained during the study may be published, any information I provide is confidential (with one exception – see below), and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. | Yes | No |
| I understand that the researcher may be required to report to the authorities any significant harm to a child/young person (up to the age of 18 years) that he/she becomes aware of during the research. I agree that such harm may violate the principle of confidentiality. | Yes | No |

| | | |
|--|-----|----|
| I agree that extracts from the interview may be anonymously quoted in any report or publication arising from the research | Yes | No |
| I understand that the interview will be recorded using digital voice recorder | Yes | No |
| I understand that data will be securely stored | Yes | No |
| I understand that the information provided can be used in other research projects which have ethics approval, but that my name and contact information will be removed before it is made available to other researchers. | Yes | No |
| I understand that I may contact the researcher [or supervisor] if I require further information about the research, and that I may contact the Research Ethics Officer of the School of Sociology and Social Policy, University of Nottingham, if I wish to make a complaint relating to my involvement in the research. | Yes | No |
| I agree to take part in the above research project. | Yes | No |

| | | |
|---------------------------------------|-------------------------|-------|
| _____ | _____ | _____ |
| Participant's name (BLOCK CAPITAL) | Participant's signature | Date |

| | | |
|--------------------------------------|------------------------|-------|
| _____ | _____ | _____ |
| Researcher's name (BLOCK CAPITAL) | Researcher's signature | Date |

Appendix C. Pen portraits

I now present brief descriptions of the participants.

Andrea, 64, retired schoolteacher. Andrea felt that in many ways her experience as a lesbian was different to that of straight women. For example she said that she resented the assumptions that were made about her such as being asked about her grandchildren and did not feel inclined to explain why she has none. Andrea said that she was happier with her physical self since her double mastectomy. She does not wear women's clothes and had not worn a bra since she was in her 20's. Andrea talked a lot about the aftermath of breast cancer and the way she had to manage other people.

Barbara D, 61, retired. Barbara apologised for the way she cut from different times in her interview and was pleased with my description of it as a 'chaos narrative' (Frank, 1995). She said that she had never had the chance to tell her story from the beginning and was getting fewer opportunities to talk about breast cancer as time went on. Although she can talk to her husband, Barbara said that he would chip in so it was good to simply tell her story uninterrupted. The main thing she kept repeating was how irritated and how impatient she had become.

Barbara PK, 80, retired. Barbara told me that breast cancer did not disrupt her life too much because the treatment did not cause much inconvenience and the changes to her body were not important 'at my age'. Her life was more disrupted by diabetes which has caused her to be blind in one eye. Barbara attributes her breast cancer to fumes from a nearby laundry. She said it would have been worse if her children had been young when she was diagnosed. As it was, they were both married so she did not feel the weight of responsibility.

Carol, 50, not employed. Carol's was a very different experience because prior to having breast cancer she had been ill with neurological problems which doctors had been unable to diagnose successfully. She told me that she had been accused of the illness being 'all in her head', which she found deeply distressing. Consequently her diagnosis of breast cancer two years later came as a relief because she was being taken seriously and being treated. She still has ongoing problems but it seems that breast cancer was not as disruptive as her previous medical condition.

Catherine , 47, *volunteer for breast cancer charity.*

Catherine's main concern was the negative impact it had on her family, specifically her son who has been diagnosed with ADHD. Catherine's mother died a few months before her diagnosis and consequently her son became very anxious during her treatment. She felt that the resulting disruptive behaviour was not dealt with sympathetically by his school. This issue is ongoing, and during the interview he was in the house and would interrupt periodically. As a trained counsellor, Catherine was eager to find ways of helping other women to adjust to life post-treatment.

Connie, 51. *Previously worked as a swimming instructor but had to give it up after her mastectomy.* The main themes of Connie's story were the impact on her body image and the positive attitude she was determined to have. Connie gave me some newspaper cuttings showing the work she has been involved with to preserve the rights of women with breast cancer to be treated on a female-only ward and her involvement in campaigning for yearly mammograms. Connie was quite critical of reconstruction and said that surgery has affected her sex life because she has never felt the same about her body.

Gabrielle, 45, *Counsellor.* The main features of Gabrielle's narrative were the breakup of her marriage and the story of her spiritual experience after her surgery (see chapter 4). It was important for Gabrielle that I included this as she told me that she felt this was the reason why she had not died. She urged me to 'use this experience, please don't let me down'.

Jean, 72, *retired.* As she had been through it twice, Jean felt she had a lot to say on the subject. Despite her age, Jean is very fit and active which seems key to her recovery from the 'horrible time' when she said she was like a zombie for weeks after diagnosis. Jean said that after she climbed Scafell in the Lake District she felt able to do anything she set her mind to. The interview lasted just 1 ½ hours because she did not become sidetracked. She said she had been thinking about what she was going to tell me ever since we had arranged to meet and had discussed her experiences with a friend for the first time.

Joy, 63, *retired.* I was at Joy's house from 10am - 3pm. Joy talked more or less non-stop, seemingly relishing the chance to talk. She gave long, involved descriptions including exactly what everybody said. The first hour that I was there, which was not recorded, Joy talked about her home improvements,

and her son's home and career. This was in response to my intended ice-breaker.

Joy told me that she was happy with her decision to have a mastectomy but that other people (particularly her husband's cousin) seemed to feel the need to question it. The repetition of this story was a striking aspect of the interview.

June, 73, retired. June wrote to me in response to the newspaper article enclosing her family tree. She lent me a book she had written about breast cancer in her family which she hopes may help future family members. June blamed herself for her daughters' cancer, saying she felt less guilty once she was diagnosed.

Although June told me that she had suffered some anxiety she was very relaxed in the interview and showed me photographs and documents. June and her daughters are particularly keen to establish a familial link. There seems to be an expectation that all the women in their family will be affected eventually.

Karen, 43, social worker. When I interviewed Karen she was due to have her penultimate chemotherapy session the next day and was bald. The main time this bothers her is in her immediate neighbourhood as she finds complete strangers easier to cope with.

Karen said she was a bit teary and started to cry when recalling her diagnosis. As a former nurse, the terminology was familiar to Karen and she was irritated that her surgeon thought that she would not understand the pathology report that she asked to see.

Karen told me that she had found it cathartic to talk to me and that it was the first chance that she had had to tell her story. She is particularly worried about possible side effects of hormone treatments.

Karen told me that she has carried on working during her treatment to avoid being consumed by the cancer identity.

Kate 47, University manager. Kate claims not to be shocked by the diagnosis, yet she used the word 'shock' 24 times. She kept stressing that it had not changed her life.

Kate had difficulty remembering the sequence of events. She was most angry about the reconstruction which continues to cause her problems. She regrets not being more assertive. However she was pleased to have rejected tamoxifen which

seemed to represent a daily reminder of breast cancer. This seemed to be important for resuming her 'normal' life.

Maggie, 56, careers adviser. The interview with Maggie was short and did not go smoothly; Maggie seemed to be unsure about how much she wanted to tell me. Maggie's main concern was for her children who were aged 9 and 12 at the time of diagnosis. When I revealed that my sons were similar ages when I was diagnosed it seemed to make things easier.

Although Maggie said that she was usually very private about her breast cancer experience, she revealed that her sex life had been affected by bodily changes which had affected her confidence.

Malaika 45, unable to work due to disability. Malaika was very friendly and talked easily without the need for many questions. Malaika talked about the significance of language used by doctors e.g. 'simple' and 'lucky.' Some weeks later we visited the support group together. Malaika told me it had been beneficial to talk about her experiences; also it had enabled her to broach the subject of her need for care after her next surgery, with her mum.

Martha, 58, university manager. Martha had warned me that hers was a bad experience. Listening to her left me feeling exhausted. She was very down about the whole experience. Where most people were impressed by the hospital's speedy treatment, for Martha it was inconvenient to have return to hospital so soon. It was an interesting interview in terms of contrasting experiences. The disruption to her physical body was minimal yet ongoing pain and tiredness have impacted significantly on her life. Martha felt that her identity was severely disrupted. From being the healthy one in the marriage, she now feels vulnerable. Martha seemed worn down.

Nina, 53 local government officer. Nina described how she was wrongfully arrested 7 months before being diagnosed which she believes may have caused the cancer. The arrest had a big impact on her confidence and her personality and her daughter wants her to be 'like she was before'. She said that talking to me is part of that process, and is the reason she is considering reconstructive surgery. Unlike some participants, Nina reported that she does not feel any less womanly with just one breast, and is grateful that she has not lost an arm or leg. The interview lasted 4 hours. There were several stories interweaved and it fluctuated from past to present.

Phoebe, 45, librarian. I knew Phoebe slightly from the breast cancer support group. She was the first person to respond to the press release on the website. The interview in the staff club lasted for 3 hours and covered many topics. The most surprising thing she talked about was how she was bullied when she returned to work. Apparently her duties had been changed to incorporate shelving books but her operation meant that she could not do it. Phoebe said that two women held this against her and even though they were aware of her surgery, spread rumours and generally intimidated her. Phoebe reported that this was worse than the cancer and that she was subsequently diagnosed with depression.

Ruth 59, teacher. Ruth was accessed through one of the students in my office. The interview took place in Hereford which is the nearest town to her home in Wales. Ruth met me at the station and I interviewed her over lunch. She recounted her difficult time with chemotherapy and depression after the treatment ended. She thinks she won't live for very long so she is making the most of life. The cafe was next to the *Haven* breast cancer charity where Ruth had received various complementary therapies during her treatment. We visited them and they told me about the support they offered at all stages. When I was there, there was a talk on lymphoedema. The *Haven* seems to offer a good service including a breast cancer nurse available to answer questions or discuss anxieties. It seems to be a good middle ground between medical attention and support groups.

Sam, 42, works from home for a charity. In contrast to the majority of the interviews where women have been very pleased with their treatment, Sam was very angry about what was happening to her. It seems she was told to stay the weight she was (just over 10st) so that she would have sufficient fat to use for reconstruction. However, she reported that subsequently she was told that she was too fat for the operation. She then lost half a stone, only to be told that she had insufficient fat and he didn't know what to do with her. As she has heard nothing for several weeks, Sam said she is feeling very frustrated because she feels unable to get on with her life until she has the operation. She wonders if he knows she doesn't have long to live. It seems that Sam's body image is very important to her, more than she acknowledged before getting breast cancer. It has affected all parts of her life and identity and Sam is not happy. She is using her experience to help other women by being a patient advocate and would like to get more involved with offering support. It was sad to hear Sam's story.

Sandra 58, librarian. Although she had breast cancer, the lump was above her breast therefore her breast was unaffected by surgery. Consequently few of the issues around embodiment cropped up in her narrative. Sandra said that she had not been afraid of treatments because of her religious faith. She believed that she was being looked after. Whenever she hears about someone having breast cancer she contacts them to offer her support. In fact, Phoebe said that Sandra was her main source of information and support after her own diagnosis.

Sophie 49, university manager. I interviewed Sophie in her office in the university where I am based. It lasted less than an hour because she had a meeting scheduled. She was very positive about the whole experience. When I told her about my own experience she told me that she was pleased to have found someone who understood what she meant. She asked to meet me again to have a two-way discussion rather than the monologue that she had just done. When we met for lunch a few weeks later, she talked about a character in *Coronation Street* who had had breast surgery and was embarking on a relationship with a new partner. The issue of her altered body had not come up, which Sophie found disappointing. She said that anyone watching would think that she (Sophie) had made a big fuss over nothing.

Viv 44, works part-time for her husband, a self-employed builder. Viv contacted me after hearing me on the radio. She seemed quite unhappy and said that she worried all the time about recurrence. I asked if she had sought counselling or support from one of the cancer charities but she said she hadn't because she didn't want to be associated with that identity ('cancer victim'). Also online forums had people talking about secondary cancer, which she found frightening. Viv said she coped by not talking about it, although she seemed to want to because she was upset that her family seemed to have forgotten what she had been through. She was worried about upsetting her family by revealing how unhappy she still was. She cried when talking about her fears for her children when she was diagnosed. She feels less worried about dying and leaving them as they get older. She has spent all of their life savings on a car and on holidays.

Viv used words like 'terrible' and 'freak' to describe her appearance and said she never let her husband see her naked and avoided seeing herself in the mirror. She felt she was old before her time and that although she previously had a good

sex life, now she wouldn't be bothered if she never had sex again.

Viv said it helped her to talk to me. I urged her to contact one of the helplines because I could see changes in her once we had talked, particularly after I shared my experience with her. It was sad.

Wendy S. 57, *part-time teacher of deaf children*. Wendy said that although she couldn't fault her physical treatment, she felt that there was a lack of psychological support. She felt that the surgeon seemed to dismiss her worries which she felt were justified.

Wendy was concerned about her sister Eve who has bipolar disorder and was diagnosed 3 months after Wendy. Apparently she found the whole experience very distressing. I felt unable to explore this as it wasn't Eve herself who was telling me.

Wendy feels like a fraud because she 'got off lightly' compared to women who have chemotherapy. When I revealed my story, Wendy thought that I must be irritated by women like her.

Wendy Y, 51, *nurse manager*. Wendy chose to be interviewed at work. She said this was her first opportunity to tell her whole story and found it very cathartic. The main theme of Wendy's interview was her surgery which she said had been done very well but she felt frustrated that people ignored her preference for 'saggy' big breasts, assuming that she wanted small pert breasts. She reported that she felt objectified by doctors admiring their handiwork and wanted somebody to acknowledge her grief. Wendy also felt that her experience was somehow undermined as it was **only** DCIS. As a health professional, Wendy was clear about the changes that could be made to women's treatment.