Narratives of women's breast cancer experience and how this impacts on their working lives

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October 2016

Abstract

Over 55,000 new breast cancer cases are diagnosed each year and the figures are rising. Most studies show that women want to get back to 'normal' and describe how returning to work helps to achieve this. For some, there are wider health implications which may affect their mobility or return to work (RTW). Disabilities are sometimes hidden, for example fatigue and emotional stress may result in a loss of confidence and work ability. Few studies focus on how the structural relations of organizations impact women's decisions to RTW after treatment. This study contributes to our knowledge and understanding of how employers view disability, how work place adjustments are made and the support that women are offered on their RTW.

This study explores the process of return or non-return to work after breast cancer diagnosis and treatment. It examines the relationship between the personal narratives of women with breast cancer and discourses around workplace discipline and practice. It records women's attitudes towards work, their career aspirations and how support networks played a part in influencing their return or non-return to work. It illustrates how women's embodied experiences are not only about immediate experiences located in a specific context i.e. the breast cancer diagnosis but also how the body intersects with culture: how it is marked by categories of gender, age, class, ethnicity, and (dis)ability and is subject to regulation and control.

Interviews were conducted with sixteen breast cancer respondents and HR directors from five major employers based in the South West of England. The cases in this research show that women's safe return to work is limited due to employers' lack of understanding of their working [dis]ability with few or no adjustments in place to accommodate their needs. Breast Cancer patients consider a RTW allows them to move on from their cancer diagnosis but struggle to overcome the barriers in the process of returning. Whilst some women struggled to retain their jobs, others changed career paths or retired early due to ill-health continuing long after diagnosis.

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Acknowledgements

My greatest debt is to the women who took part in this research project which would not have been possible if I had not had the good fortune to share in discussion their experiences of how breast cancer impacted their lives. They gave up their time generously and I wish to thank them for this. I warmly acknowledge the support and encouragement of my supervisors, Irene Gedalof and Leroi Henry - their advice and guidance has been invaluable. I would also like to thank the staff and students, past and present, at Working Lives who have created a stimulating and enjoyable learning environment for the past five years. They have created stability during troubled times. My deepest gratitude goes to my family who have provided reassurance during periods of uncertainty and supported me through to the end.

Introduction

This doctoral thesis is the result of a five year research project with the last two years conducting field work in the South West of England on how women return or don't return to work after breast cancer. Over 55,000 new cases of the disease are diagnosed each year which results in more and more women being taken out of work. This may mean a temporary or permanent loss of employment and/or work ability. The high number of incidents occurring each year resonates experientially with me as I became a breast cancer statistic 25 years ago. This has allowed me to become both an insider as a breast cancer patient whilst conducting interviews with the women and also an outsider as a researcher practicing sociology with a critically reflexive eye. For several decades my work as a feminist sociologist and teacher/researcher has focused on gendered health inequalities and sustainable work practices for women. I have been an active Trade Union Member for nearly 40 years promoting women's equality in the workplace. I bring to this project 'situated knowledge (Haraway,1988) and experiences'[1] which I have critically reflected on in my research journal throughout the project, some of which are incorporated in my analysis.

Thesis title and overview

Narratives of women's breast cancer experience and how this impacts on their working lives

This research aims to enhance the literature on RTW after breast cancer. My approach regards a RTW process as involving much wider health implications than a single focus on work attendance which starts and ends as soon as breast cancer patients return to work. For some women there are wider health implications which may affect their work-ability and which are sometimes hidden.

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[1] Cotterill and Letherby (1994:143) state there is a 'need to acknowledge the 'person' in the researcher.

For example, the emotional stress and trauma is often on-going for some patients as they may continue to fear the return of the disease resulting in a loss of confidence.

Breast cancer is the most commonly diagnosed cancer in women in the UK - one in eight women will develop breast cancer at some point in their lifetime.[2] Approximately 1,000 women still die of breast cancer every month in the UK. In 2014, there were 3,224 new cases of cervical cancer in the UK, 7,378 new cases of ovarian cancers but resoundingly high were the number of new breast cancer cases reported of 55,222.[3] The breast cancer figures raise concerns not only to medical professionals (regarding the cost of treatment) but also to sociologists of health and of work because of the increasing number of women being taken out the workforce either temporarily or permanently sometimes due to the disabling effects of treatment.

One of the major concerns for women with breast cancer is not only coming to terms with the disease but also the problems associated with body image. Gender role socialization has influenced how women think about their appearance after breast cancer and feminist researchers like Eve Kosofsky Sedgwick (1999, p.154) who uses her own experience of breast cancer states, it is "not surprising that gender is so strongly, so multiply valanced in the experience of breast cancer today [and] plunges one into an experience of almost archetypal Femaleness". She highlights the importance of using the experiences of women to explore their disease which supports Smith's notion of looking out from where our respondents are. My research supports this and has shown the importance that some women place on breast loss and how this affects their femininity and sexuality which I discuss in chapter 5, section 5.5. Some women mourn the loss of their breasts for quite a long time after their mastectomy. For

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[2] http://breastcancernow.org/about-breast-cancer/what-is-breast-cancer/breast-cancer-statistics.

[3] Cancer Research UK

some, it is like losing a limb. Others feel they are rushed into breast reconstruction without time to adjust to their changed bodies. Research on body image in previous studies does report how some women struggle with breast and hair loss but it fails to take account of the emotional effects this has on women which affects their identity and confidence in themselves as they return to work.

There are certain standards by which body image is measured that "reinforce present-day cultural normative ideals of attractiveness" (Boquiren, et al, 2013, p.2178) and women are encouraged to live up to these. Those who invest the most in these ideals have "greater difficulty in adjusting post treatment and reported bodily dissatisfaction and poorer mental health than those who held lower levels of investment" (ibid). Those who cannot live up to the body distortions after mastectomy exhibit dissatisfaction which often leads to feelings of shame.

The internalization of gender roles may lead to breast cancer survivors experiencing physical symptoms such as powerlessness, frailty and weakness which Boquiren et al (2013, p 2182) suggest lead women to feel they can "no longer trust their body (functioning) or that their bodies betrayed them". On top of the trauma of diagnosis and treatment of breast cancer women are faced with the "specificity of loss, due to the links between breasts, female identity and sense of self" (Manderson and Stirling, 2007, p.76). Their distortions are a constant reminder of the relationship of the body to self-image, gender identity and sexual expression" (ibid) and the fear of a recurrence is always present.

The effects of breast cancer surgery and adjuvant therapies can impair women's sexuality and cognitive behaviour as well as the additional problems of weight gain. Biglia, et al (2010) state that some women reported memory loss, lack of concentration ("chemo brain") and weight gain after chemotherapy. The authors suggest "psychological consequences in breast cancer survivors have been neglected in medical literature for a long time. Sexual dysfunctions in women

with breast cancer were mentioned in the 1970's for the first time" (p.1897) but women are still reporting problems related to early menopausal symptoms such as hot flushes and vaginal dryness following chemotherapy.

Women also experience physical impairments – one of the most common is lymphoedema but other impairments such as neck-shoulder pain and muscle weakness sometimes continued up to two years after operation (Kärki et al, 2005, p. 180). Their study also found that patients at 6 and 12 month follow-ups experienced participation restrictions at work. They found reduced work ability can "also lead to earlier retirement and increased sick leave" (Kärki et al, 2005, p. 185-187).

All cancers can affect sexuality but the specific concerns that apply to breast cancer patients "extend beyond the ability to have intercourse, and includes ideas of body image, femininity, desirability and childbearing capabilities. It has strong emotional, intellectual and sociocultural components" (Henson, 2002, p.262). Thus, while breast cancer shares many of the same characteristics as other forms of cancer and disability, and women returning to work after breast cancer face similar challenges to other cancer patients, it is also important to recognise its specificities, particularly as they relate to women's sense of their gendered identities. Little attention is paid to these problems when women return to work. This research aims to fill the gaps particularly in trying to understand issues of embodiment that affect women's identity as they return or do not feel able to return to work.

After an extensive review of the empirical literature on women's RTW this project follows feminist research practices which focus on embodiment and experience and relations of ruling. My research draws on the work of Smith (1987) and Bourdieu (1977) who provide a framework for exploring the 'relations of ruling'

and 'invisible structures of power' and which has resulted in the formulation of the following research questions:

1) How do women who have had breast cancer construct personal narratives of the disease, how do these contrast with dominant medical ideologies and models and what is the impact of these ideologies and counter narratives?

2) What is the relationship between the personal narratives of women with breast cancer and workplace discourses and practices in women's employment?

3) How do women navigate 'the invisible structures of institutions' or 'ruling relations' on their return to work after breast cancer?

The literature reviewed in this research project shows that some women with breast cancer suffer discrimination at work (Macmillan 2013), and report a lack of support from supervisors with few mechanisms in place to facilitate their return. The studies show that employers need to be more aware of the effects that cancer treatments have on women with breast cancer and offer more support in helping them return (Lindbohm 2014, Johnson 2010, Damkjær 2011, Gudbergsson 2009). My primary data supports current literature in this field reporting a lack of sympathy or understanding from employers directly (through personal dialogue) or indirectly (through workplace policy and practice) about returners' work [dis]ability. Empirical studies also report lack of support for breast cancer respondents from work colleagues who may have to shoulder extra work responsibility during cancer rehabilitation periods although this was not evident in my research. Women with breast cancer report that they want to get back to 'normal' after treatment and return to their jobs as soon as possible but there are those who struggle to return or to retain their jobs. For whatever reasons women return or don't return after breast cancer, little attention is paid to how the wider social relations impact their decisions.

Chapter one discusses some relevant theoretical perspectives and models of health and illness within a wider socially scripted health agenda involving structures of power and control impacting women working with breast cancer. It

summarizes how health can be understood in relation to the dominant paradigm of western medicine and how sociological issues have stemmed from this paradigm. The evolution of biomedical discourses generally is relevant to the understanding of how breast cancer patients become disciplined and normalized and how their beliefs are shaped within the constructs of disability. It shows how certain medical knowledges are privileged whilst others are subjugated. This chapter also explores media and cultural discourses around breast cancer and argues that it is almost impossible to disentangle what is biological and what is cultural and how women's embodiment, knowledge and experience shape their thinking.

Chapter two provides a context for my primary research which includes information on the breast cancer movement and also the legislative policy context around breast cancer and return to work in contemporary Britain. It explores the roles that various charities and stakeholders play in promoting government health reforms.

Chapter three examines a selection of scholarly research about women's breast cancer experience and their RTW. It follows the main themes of my research: knowledge construction, return to work and workplace practices which are discussed in relation to my research findings. Blind spots are highlighted and I show how this literature ignores the lived experiences of women in relation to how they navigate 'the invisible structures of institutions' (Bourdieu, 1977) or 'relations of ruling' (Smith, 1987, p17) on their return to work after breast cancer.

Chapter Four discusses research design and methodology and describes why the methods chosen are appropriate for this research project. It explores the practical application of the chosen research design and discusses some key methodological issues. It reflects on specific challenges and limitations of the project.

Chapter Five, the first of three findings chapters, explores how women construct personal narratives of their disease and how these contrast with dominant medical ideologies and models. It starts from how women experience breast cancer diagnosis, how they access medical information and how they make sense of this in relation to their own lay knowledge and experiences. It looks at loss of identity through surgical changes to their bodies and how this is manifested both physically and mentally.

Chapter Six examines the process of return or non-return to work after diagnosis and treatment (sometimes during treatment). It examines how women's attitudes towards career aspirations may change after breast cancer diagnosis and treatment and how support networks play a part in influencing a return or non-return to work. The women's breast cancer experiences are located in a specific context i.e. RTW which explores how the body intersects with the cultural experiences of work and disability.

Chapter seven explores how employees are managed on their RTW. Through interviews with the HR directors of major employers in the South West of England it examines workplace cultures, policies and practices which illuminate the institutional field within which women returning to work after breast cancer are regulated and controlled. This information is contrasted with interview data from breast cancer respondents and although not matched, can highlight how they respond to institutional relations of ruling.

Chapter eight concludes with a summary of research findings, contributions and limitations and my reflections on the project.

Chapter 1

Theoretical Perspectives and models of health and Illness

1.1 Critique of the evolution of biomedical discourses

Current research on gender and health has been criticised for the lack of attention paid to theoretical developments in the social sciences since the late 1970's. Annandale and Hunt (2000, p.71) state there is a need for future health research to go further than the 'social scripted' agenda which is sometimes limited by its methodology and focus and stress that narrative data generated through qualitative research offers insight into relationships between gendered health and the wider "relationships and structures of power and control" (Annandale and Hunt, 2000, p.77). This chapter identifies concepts and theoretical approaches that raise useful questions which I aim to explore through my own empirical findings in relation to women returning to work after breast cancer.

Firstly, I examine the evolution of a bio-medical discourse and explore issues around disciplining and normalizing tendencies and self-surveillance. I explore how the dominant ideologies and power relations impact on women's health and work ability through legislation and workplace practice. Secondly, I briefly critique media and cultural discourses of breast cancer and examine how language is used to describe cancer and how this shapes our conceptions of illness. Thirdly, some phenomenological accounts of lived experiences of breast cancer are offered arguing that our biology is more 'fluid' and includes the cultural and social body. How are beliefs about health and illness shaped?   In particular, how do women with breast cancer construct personal narratives of the disease and how do these ideas contrast with the dominant medical ideologies and models. According to Nettleton, the sociology of health can be understood in "its relationship to the dominant paradigm of western medicine: biomedicine" and many sociological issues have stemmed from this paradigm. (Nettleton, 2006, p.2) According to Nettleton, from early childhood experiences and throughout our

adult lives we piece together certain beliefs about health and illness according to our own experiences coupled with professional knowledge, mediated by technology and science. Simply put, the biomedical model is based on certain assumptions. Firstly, it is based on dualisms whereby the mind/body can be treated as separate medical problems. There is a tendency to generally divide concepts into binary oppositions: health/illness, man/woman, public/private, which creates difficulty in separating their meanings. Usually the first in the binary pair is in some way superior and more desirable than its opposite other.

Following the medical model, a diseased body is something that must be cured. As Foucault (1976) states, rational medical discourse constructs bodies as normal or pathological: the latter becomes matter out of place. The physical body, when diseased, is seen as object-like, disqualifying or discounting the agency or subjectivity of the embodied self as it becomes medicalized. Secondly, the body is likened to a machine – the dysfunctional part can be repaired by medical engineers (doctors). Thirdly, this leads to an over-reliance of technology, known as a *technological imperative*. Fourthly, the medical model is reductionist and "…privileges such explanations at the expense of social, cultural and biographical explanations…the individual patient is a more or less passive site of disease manifestation" (Atkinson, 1988, cited in Nettleton, 2006, p. 2-3).

Certain medical knowledges are privileged whilst others are subjugated according to Foucault (1980). He describes subjugated knowledges as knowledges that are created in conflict or struggle and whose conflict has been erased as these knowledges have been "buried and disguised in a functionalist coherence or formal systemization" (Foucault, 1980, p. 81-82). Furthermore, he suggests that subjugated knowledges include:

> a whole set of knowledges that have been disqualified as inadequate to
> their task or insufficiently elaborated: naïve knowledge's, located low down
> on the hierarchy, beneath the required level of cognition or scientificity
> (ibid).

According to Foucault there are three main instruments in the relations between power and knowledge. The first is hierarchical surveillance where subjects are observed in institutions which are designed to facilitate observation such as schools, hospitals and prisons. The second instrument of power is through normalization. Actions or attributes are compared so that a norm can be established. The judges include teachers, doctors and health workers etc. The third is a combination of the first two where the subject can be measured and corrected (Foucault, 1979, p. 304). For Foucault, it is necessary to excavate patterns of how power is exercised rather than who has power. He believes that power is constituted in discourses – it is everywhere and cannot be possessed by men (Foucault, 1980 cited in Ramazanoglu, 1993, p. 20). However, we cannot ignore the fact that those people who hold powerful positions construct and transmit certain knowledges which become dominant and taken-for-granted about what is 'true' in society.

Dorothy E. Smith's (1987, 1999, 2006) work on 'ruling relations' raises important questions about one of feminism's central concerns, critiquing discourses which sustain a patriarchal social order i.e. relations of power that systematically privilege one social group over another. It involves examining how gendered relations are (re)produced, negotiated and contested in social relationships between people and in their social and personal identities in text and talk. The taken for granted commonsense assumptions and normalcy of gender obscures the power differences and inequalities which are at work within the hidden structures of power. It is one of the most useful feminist theories and an important driver of this research. Smith (1987, p.54) states:

> …The class that rules the society by virtue of its domination ...organizes, and sanctions the social relations that sustain its domination.

She was concerned about who produces what and for whom. Her interest was in the things that come to us from outside and which do not come directly from out of our experience. Smith describes the relations of ruling as a "complex of organized practices including government, law, business and financial

management, professional organizations and educational institutions as well as the discourses in texts that interpenetrate the multiple sites of power" (Smith, 1987, p.3). The dominant mode of ruling continually transcribes the local and particular actualities of our lives into abstracted and generalized forms, which she refers to as an extralocal mode of ruling. Its relations are governed by organizational logics. The distortions of this rational process (e.g. hidden gender bias) are created by men's sexism and the social construction of gender means that women are excluded from the practices of power within these textually mediated relations of ruling. For example, sociology is part of the ruling apparatus, the institutional forms of ruling constitute its major topics: the sociology of organizations, education, health, work, law and so forth. It is still busy clarifying, organizing, mapping and extending the relations of ruling. But it does not map the unknown which is why Smith advocates starting from the standpoint of women in the actualities of their everyday world. She suggests, we can "look out from where we are, from where our respondents are onto the larger landscape organizing and containing their daily practices" (Smith, 1987, p.183; 2004, p.76). This is an important point in relation to my breast cancer respondents because starting from the standpoint of women, moving from their breast cancer diagnosis to a return to work is, more often than not, fraught with external relations which I discuss in Chapters 5, 6 and 7.

Smith strongly advocates that we must question the forms of knowledge which are taken for granted "hence knowledge must be differently written and differently designed if it is to bear other social relations than those of ruling", organized so that it "extends their own good knowledge of the local practices and terrains of their everyday/everynight living" (Smith, 2004, p.94). Furthermore, Smith sees sociology as being of the "same lived world of which it writes" (Smith, 2004, p.97), we are both in and of the social but we are, in the main, abstracted from our local settings. She states:

> We go to work as sociologists: we enter this world organized in and through texts as we sit down to the computer to write, as we work our way through a stack of papers to grade...looking for ideas for teaching...We don't even think of it as a world of relations and

ourselves as outsiders...it has an ordinary existence... (Smith, 2004, pp.49-50).

This taken-for-granted objectified world in common which is vested in texts are all part of the activities and decisions made by large scale organizations, the super-structures of business, "symbolically constructed" through technology and which separates us from what we know as individuals and what we are trained to know which is external to our particular lives (Smith, 2004, p. 50).

Following Smith, DeVault and McCoy (2006, p.15) investigated ruling relations using interviews which they say are not just sources of learning about women's individual experiences but can also form part of the research to investigate organizational processes that "reveal the relations of ruling that shape local experiences. I follow Smith's idea of focusing on "text-mediated relations organized around specific ruling functions" which in the case of my research is to examine whether the policies and practices laid down through talk or text in organizations facilitate or constrain the safe return of breast cancer patients as they return to work after treatment. What comes into view through ruling work is what Devault and McCoy describe as:

> a vast nexus of coordinated work processes and courses of action - in sites as diverse as hospitals, homes, doctors' offices, community clinics...workplaces...pharmaceutical companies, advertising agencies, insurance companies, government ministries...mass media and medical and nursing schools (DeVault and McCoy, 2006, p.17).

My research seeks to bring into view some of these relations. Although this project is not conducted on the same institutional ethnography scale as Smith's inquiries, it nevertheless seeks to move along similar lines beyond "the interchanges of frontline settings" to explore how HR Managers of organizations at a local level understand the needs that are specific to breast cancer patients and their return to work after treatment (DeVault and McCoy, 2006, p.29). I have also been able to learn more about ruling relations from the breast cancer respondents' narratives – the constraints they identify in their return to work and

experiences which reveal how the relations of ruling operate. They reveal that HR managers are not aware of disabilities such as cognitive impairment suffered after treatment or physical disabilities like lymphedema which may develop at any time after breast surgery. When employers do not offer a clear back-to-work plan or make adjustments to facilitate a safe return, and when there is no dialogue taking place with their managers, this causes emotional stress as the respondents struggle to adapt both to their changed bodies and to coping with 'normal' work-loads which employers often expect them to cope with on their return. Work expectations and work ability are problems that have been identified in many studies but with no relation to functions of relations of ruling – only that they exist. Problems arise from employment relations and/or contractual obligations due to the lack of understanding that managers have in both interpretation and implementation of the 2010 Equality Act. For example, some breast cancer respondents work through treatments because they are not informed that they are entitled to take time off work for treatment or hospital appointments.

Another useful concept that this research draws on, particularly in my data analysis chapters, is Bourdieu's social theory of habitus field and capitals. This is important in the analysis of how breast cancer respondents from a working class background may lack 'cultural capital' compared to the breast cancer respondents from a middle class background, particularly in relation to their role and employment status which I discuss in chapters 5, 6 and 7.

Firstly, to understand Bourdieu's concept of capitals it is wise first to understand the concept of the 'habitus' and 'field'. We can think of the habitus as assimilated and transposable 'schemes of thought' which act to link subjectivity and structure without reducing either to the other. (Bourdieu 1991, p.5). Within his theory of the habitus Bourdieu describes how cultural reproduction supports and maintains class relations. The habitus is transformed by pedagogic messages transmitted through the family, schooling and work. It establishes divisions between sexes and labour.

> In a class society, all the products of a given agent...speak inseparably and simultaneously of his class - or more precisely, his position in the social structure (Bourdieu, 1977, p.87).

The strongest elements of the habitus occur in early childhood experiences. They are without question - unconscious. We adopt ways of knowing and being, acquiring taste, attitudes and learn 'the rules of the game' which become second nature (Bourdieu 1977, p.72) and are practiced over a long period of time. Bourdieu sees the family as a fiction and a social artefact, a well founded illusion because it reproduces and maintains these relations with the guarantee of the state and 'operates as a central site of normalization and naturalization' (Skeggs, 2004, p.21).

Firstly, the social body can be analysed using Bourdieu's concept of habitus – the self which is socially produced. Probyn (2004, p.232-233) reminds us that habitus was a concept which was initially a sociological concept used medically by Mauss (1990) to describe the outward appearance of the face in relation to its internal state of health or sickness" (Probyn, 2004, p.233). It is interesting also that Mauss was attempting to form a vision of a sociological accounting for totality in which he called for sociologists to "reconstitute the whole" (ibid). Mauss thought that this could be achieved by analysing the physiological, psychological and the social in order to understand the whole person. Within this tripartite relationship Mauss advocates the social not as something that is imposed or internalized. Rather, the collective totality should understand the social needs as an internal necessity to understanding the whole body. More importantly, Probyn states that within the picture of embodiment, "the body does not fall away before the social...the social here is charged with physicality" (Probyn, 2004, p.235). Although Bourdieu does not elaborate on how the body is in the social, others have teased this out of his work on the habitus. For example, Marshall (1999, p.71) in *Our Bodies, Ourselves* shows how the body which she describes in her data "is as social as it is individual" as the body is both created and recreated through social interaction. Our bodily experiences always involve dialogue in which we should ask "who else is there - literally or in imagination" (ibid). Marshall

cites Reay (1995) who highlights how Bourdieu's (1981) concept of habitus has demonstrated "not only the ways in which the body is in the social world but also the ways in which the social world is in the body" (Marshall, 1999, p.61). Using the habitus allows us to assemble new ways of thinking about the social world. For example, Bourdieu's work, "like the very thing it aims to capture, should not be considered as fixed or external but rather an evolving idea" (Grenfell, 2012, p.63).

My research adopts the idea of body totality. Just as Mauss talked of the feeling body which he saw as part of the physiological component that makes the body totality, so too the social body must also encompass the wider social world and its outer social problems. Through our sick bodies we experience the psychological pressures of everyday life and take these into the social world. In the case of this research my breast cancer respondents experience the physiological, psychological and social effects of the body as they return to work after treatment. The emotional stress involved in reconciling the breast cancer and taking this into the social world of work takes on new meaning as women have reported in this research.

In Bourdieu's habitus actors are equipped with the 'know how' or the 'rules of the game'. We take up spaces, know about styles of dress, language and so on. It is also about attitudes and taste or a 'way of being'. Bourdieu cuts across distinctions between mind/body and conscious/unconscious. Habitus is weighted in personal, social and collective history which Bourdieu calls 'embodied history'. It becomes so internalized that it is almost forgotten – things become second nature. But it leaves an individual trace of history.

Secondly, because it is relational, habitus only makes sense in the context of specific fields. Here I stress the importance of following Marshall's idea of asking who else is out there, in relation to how breast cancer respondents enter into different fields, how they experience the relationships within the medical

profession when they are first diagnosed. They may also experience relationships with cancer charities, support groups and other agents of The Department of Work and Pensions if they are unable to work which I discuss in chapter 5. Finally, when women return to the field of work they are subjected to the relationships with their employers which I discuss in the results chapters (chapters 5, 6 and 7).

The traces our embodied history contains allow us to view how the social is organized. For example, class, race and gender can be marked as distinctions or divisions. Sometimes there is a clash and inequalities exist between different habitus. Some people make judgement on others which is only visible if it is perceived by someone who is capable of making distinctions – a person inscribed as "endowed with categories of perception, with classificatory schema, with a certain taste, this permits her to make differences to discern, to distinguish" (Bourdieu 1998, p.9).

Habitus and field have a compatibility between them although they have their own logic or rules. As the field sets limits on practice, so too can agents shape the habitus of the field. The games played in the field may involve various goods and resources of exchange value. Habitual ways of acting become routine tasks. The dispositions in turn reflect the established norms of social behaviour. The actions become so habitual that they become intuitive. Within the family children derive and develop modes of thinking and taste along the lines of stratification. These relationships are extended into the processes of schooling and later into work.

For Bourdieu (1996, p.264) the field is a structured system of social positions and also a structured system of power relations. The positions occupied have a dominant/subordinate homology to one another. They allow or deny goods or resources, known as capital which Bourdieu divides into different categories, cultural capital (knowledge and education) social capital (relations with significant

social others) symbolic capital (prestige and social honour) and economic capital (money and assets) (Williams,1995, p.587). Bourdieu stresses that capital exists or functions in relation to a field. In summary, the habitus, together with the trajectories and strategies which are produced, operate in the context of certain opportunities or constraints placed by the structure of the field itself. The field is where one form of capital can be converted into another for example, educational qualifications may lead to lucrative jobs (Bourdieu, 1991, p.14), which I discuss with reference to job role and status in chapter 7. Cultural capital is the most developed of Bourdieu's theory of capitals and he uses this to describe how the judgement and ideas of the elite class which he also refers to as the dominant group, are presented as a universal given and thus legitimize its position of power. Bourdieu uses the idea of capital to address differences in resources of power and how this determines economic capital. An agent or an institution possessing specific capitals (economic or cultural) is able to occupy dominant positions within their respective networks within the field using strategies to preserve and transform these relations of power (Bourdieu, 1996, p.265). In summary, [(habitus)(capital)]+field=practice is how Bourdieu formulates the theory of social practice (Bourdieu,1984, p.95). Social practice is produced by the relationships between one's disposition (i.e. habitus) and one's position in a field which depends on the volume and composition of capital within the context of the social space (i.e. field). In chapter 7, I discuss how capitals can play an important part in accessing health care.

Mishler sees medicine as a powerful institution dominated by physicians who are "given legitimate mandate" to carry out certain tasks and procedures. (Mishler, 1981, p.16). Because of their power, it is necessary to examine how illness is constructed and controlled. Mishler reminds us that the biomedical model is "so pervasive that it appears to be the 'normal,' natural, and perhaps the only way to think about health and illness…and everything else proposed may appear strange" (Mishler, 1981, p.250). Furthermore, shifting to a social perspective "will not change the realities of power" (Mishler, 1981, p. 253); this is dependent on "the conditions and structures of economic and political power" (ibid). However,

some feminists have challenged the medical model. Feminist researcher Donna Haraway (1991, p. 81) uses the cyborg model in many different frameworks to destabilize language with particular reference to binary oppositions. The cyborg, drawn from the world of biotechnology is useful in terms of focusing on women's identity and their embodied locatedness. For example, Haraway's interest covers not just literary deconstruction but liminal transformation and she believes that it is possible to produce a paradigm shift – similar to the work that emerged from black and post-colonial writers, "without reference back to a single, stable origin" beyond binary systems. She "disassembles" then reassembles" the self (Haraway, 1991, p.163) which is useful in offering resources for resisting a medicalized self within bio-medical models of illness and the body.

Feminist theory sets out to de-naturalize these assumptions and unpicks the dominant power relations that impact on the lives of women particularly those working with breast cancer. Feminist discourses, according to Weedon (1987, p.110), allow women the opportunity and space to challenge dominant subject positions that can either reinforce existing power relations and subject positions or undermine and expose other positions. Resistance to the dominant begins with the individual level – it is the first stage in producing alternative forms of knowledge and to persuade others of their versions of subjectivity. The institutional practices that maintain this dominance are as a result of powerful relations of years of medical science taking one view, supported by a powerful pharmaceutical lobby. (Weedon, 1987, p.112). Radical demands have the possibility to be appropriated if they are seen to not affect dominant interest too greatly (Weedon, 1987, p.111). Butler (1990, p.41) reminds us that the body gains meaning within discourse only in the context of power relations so in discussions of gendered health within dominant medical discourses using binary logic, it is easy to understand how we have been blinded for so long by the male/ female, able/disabled labels which have prevented us from seeing the "plurality of experience that characterizes contemporary social life" (Allandale, 1998, p.153).

Notwithstanding that health is everybody's business, sociologists have recognized that the dominant medical model of health is defined quite narrowly and have recently begun to challenge biomedicine's assumptions of 'truth' about disease and state its categories and the model in general, neglect to address the social and material causes of disease. Nevertheless, that is not to say that a social model ignores modern medicine and scientific knowledge. It recognizes that health is influenced by models from many different disciplines. One of the ways of doing this is through exploring women's narratives as advocated by Annandale and Hunt (2000) which offers a unique insight into how women construct their own critique of the dominant ideologies and highlights the tensions between discourse and experience.   Their lived embodied experiences become valuable knowledges that can help us devise better strategies for coping with illness as illustrated in section three. But firstly, how is illness constructed and managed for those living with a disability?

1.2 Constructs of disability

This section explores how medical models of disability have been challenged by feminist researchers and campaigners of disability rights. Firstly, the Equality Act 2010, as it was in the Disability Discrimination Act (DDA), states that cancer is a disability from the point of diagnosis, and is highlighted in schedule 1 paragraph 6 of the Equality Act and is explicitly referenced in the Guidance on the definition of disability published by the government (Office for Disability Issues). This information is also linked through the Equality & Human Rights Commission website. Being defined as disabled mean someone with cancer is entitled to all the relevant protections including reasonable adjustments at work. However, there are many feminists and disability rights activists who challenge the ways in which disability is perceived and how the Act is implemented in both policy and practice of health care and employment.

In the present context of welfare reforms in line with austerity, there are many changes being made to welfare provision. Morris (2011, p.10) suggests we need to rethink disability policy. She suggests we have moved from welfare paternalism, an approach which operated on the basis that the "state knows best", to liberal paternalism where disabled people are encouraged to "help themselves". However, within this welfare paternalism there exist negative attitudes towards those who are not in work or "economically productive" (ibid). Morris questions the rise of the individualist framework which she suggests is undermining the welfare state. One of the problems with only focusing on independence is that the individual is seen as the problem, "most often their attitudes and motivations – which is required to be fixed" (Morris, 2011, p. 12). The changes in welfare reform seek to target resources to the most vulnerable and encourage those who are able to take responsibility for themselves. This results in a narrowing of eligibility and means-testing for benefit claims. Functions previously carried out by the public sector have moved to the private sector. Morris states:

> In the field of welfare reform, the insurance industry has both influenced the development of ideas and policies, and benefitted from the new contracted out assessments and employment support services (Morris, 2011, p. 15).

I return to the discussion on the move of health provision from the public to private sectors in relation to employment sickness and occupational health in my research findings in chapter 7. The outsourcing of both adult social care provision and employment support have become competitive within the market under the new reforms. Morris suggests that we should extend the concept of reasonable adjustments under the Equality Act, to the welfare state. She claims disabled people don't just need a safety net, they need disabling barriers lifted and recommends that involving disabled citizens fully means "redistribution needs [should] be in the context of a value system which values diversity and where disabled people are treated as belonging and contributing to the communities in which they live" (Morris, 2011, p. 16).

Within disability politics there is currently a push by some breast cancer patients who have become disabled through the disease or the treatment of it, to recognize the 'healthy' body as temporarily able-bodied to mark the precariousness of health under the regulatory powers that dictate normative standards of bodily wellbeing. But there is an "inherent leakage and instability of those categories, because the spectre of the 'other' lurks within the selfsame" (Price and Shildrick, 1999, p. 440). The authors cite Foucault's body problematic as a:

> locus of knowledge production…with medicine as a disciplinary regime through which the embodied subject is inscribed and brought into being with the circulation of power/knowledge as the indivisible condition of discourse (Price and Shildrick,1999, p. 440).

The locus of power/knowledge has shifted from the control of the 'medical gaze' to the subject's policing of her own body in order to meet the norms of health and illness. The patient is encouraged by the rules that govern medical science to freely offer information to be scrutinized to produce 'truths' about herself and at the same time, "the capillary processes of power reach ever deeper into the body, multiplying the norms of function/dysfunction". (Price and Shildrick, 1999, p. 434). For example, Price and Shildrick refer to past rules of claiming for disability allowances where claimants were subdivided by their response to questions forcing them 'into patterns of normalization which grossly restricts individuality" (Price and Shildrick, 1999, p.435).[4]   Furthermore, the patient submits to what Foucault describes as a power process that "produces domains of objects and rituals of truth" and "Power circulates in the procedures of normalization by which on the one hand the body is inscribed within the meaning (the intelligible body) and on the other rendered manageable (the useful manipulated) body" (Foucault, 1977 cited in Price & Shildrick, 1999, p. 433) These two facets make up the docile body which is subject to control through 'quasi-voluntary acquiescence" (ibid).

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[4] Price and Shildrick (1999, p.436) state, "The extent of the benefit agency's 'need' to know is indeed an expression of the power/knowledge complex that underwrites the modern social body".

Muller (1979) cited in Wendell (1996) points out that those who administer and provide healthcare services and benefits to people with disabilities are not generally people who are affected by the defining categories of disability but they hold power to make choices over entitlement (Wendell, 1996, p.24). Although the above author's work is dated there still exists tensions within disability politics in which claimants struggle to receive benefits – see for example recent posts on Disability News Service for evidence of the continued difficulties for claimants[5].

Disability in terms of entitlement to benefits and for insurance purposes, is usually narrowly defined. This results in confusion both for the provider and the client. Some people who are identified as disabled do not see themselves as such or vice versa. If a disability has no outward signs of social recognition it can result in less support being offered. Morris (2011, p. 8) also points out that in the case of illness:

> There are confusions by using the term 'disability' to refer to impairment rather than disabling barriers.

She refers to disabling barriers as unequal opportunities and access to work or "when someone loses their job because of illness and then has difficulty gaining new employment, unless they can convince an employer that they are cured" (Morris, 2011, p. 9).

Mental illness on top of physical pain is sometimes not identified by medical professionals as a disability. This non-recognition or denial of experience is a major source of loneliness and alienation, often causing despair in people with unrecognized disability (Wendell, 1996, p. 119). There still exists a stereotype in the public's mind of "total disability" and Wendell raises further concerns and

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[5] http://www.disabilitynewsservice.com/how-a-single-word-shows-dwp-has-finally-owned-up-on-benefit-deaths/.

asks, what do people with disabilities have in common and do other factors such as gender, class, race, age or sexuality impact on their existing experiences of being disabled? (Wendell, 1996, p.30). These, and many other questions are raised by Wendell in order to break down the universalization applied to all those who are classed as disabled and whose differences are ignored. Women have written about their own experiences highlighting major gender, sexuality, race or class differences which affects their experiences of disability but what is important according to Wendell, is "what meanings people with disabilities give…through their cultural interpretations and their political actions" (Wendell, 1996, p.32). However disability is defined, it is of significance socially, culturally, politically and economically. Wendell suggests, not only are we marked by gender but also by categories of class, ethnicity, sexuality and (dis)ability which regulate and control our bodies. Despite the individual focus, structures of power operate to separate the hierarchies with those who have more control of their bodies having more power over those with the least control. Failure to control the body becomes a "powerful symbolic meaning of disability" (Wendell, 1996, p.61).

Shildrick (2012, p.30) reports that critical disability studies (CDS) has made "remarkable expansion and development in little more than two decades". Furthermore, Shildrick suggests that the move towards postmodernism in CDS has changed the way we approach embodiment for all "once we take the difference of disability into account" (ibid). However, she is not saying that older constructs of disability within the social model are wrong or should be replaced but that "we should not ignore the development of post conventional theory and the changing environment" even though we cannot solve the problems that exist. We should try to understand why disabled people "continue to be the target of widespread discrimination" (Shildrick, 2012, p. 31). She adds, just as in the challenge to racism,"…(dis)ableism must be addressed both by those who are identified with normative standards, and by those who are excessive to them" (Shildrick, 2012, p.39). Using a range of theories, we must continue to ask, what differences do these make to the "othering of disabled people" so that we can move research on from using inadequate models of embodied self. Earlier

studies such as those by Weedon (1987) and Wendell (1996) have impacted my approach in this research. They remind us how certain institutional practices have dominated medical science for years and therefore if we want to persuade others that there are other forms of knowledge we must start by discussing various differences in disability.

1.3 Media and Cultural discourses of breast cancer

Whilst the media singles out brave celebrities who fight breast cancer, what of the others, as Stacey reminds us. "What of those who declined rapidly, who cried with fear and terror in the face of death, who live haunted by the threat of cancer returning or from whom there is no hope? What of those who do not smile bravely? In the success/failure binary opposites of hero narratives these people can only be seen as the failures' (Stacey, 1996, p.90). Evidence of such failures were shown in 1993 when a New York Times cover featured model Matuschka, in a dress cut diagonally, revealing her mastectomized chest with her remaining breast covered. The image was a high fashion shot, lit in such a way as to reveal the scar and entitled, 'Beauty out of Damage'. [6]

Up until recently breast cancer was primarily an illness experienced by menopausal women however it now affects a much younger age group although they are rarely portrayed by the media. We frame breast cancer by cultural understandings and conceptions of illness. We seem to view cancer with horror in Western cultures. Stacey (1997, pp.73) argues that this is partly due to the fact that cancer challenges our understanding of the body in terms of its vulnerability, its integrity and its potential for violation. She states: "the body has been understood to be constituted within and through a system of boundaries, which are integral to wider beliefs about defilement and purification" (Stacey,1997,

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[6] Matuschka, Beauty Out of Damage, New York Times Magazine, 15 August 1993; and Hollis Sigler, Hollis Sigler's Breast Cancer Journal (New York: Hudson Hills Press, 1999)

p.75). Cancer violates these boundaries and creates anxiety about the fixed subject and object, the certainty of normal and abnormal, inside and outside. Whilst cell division marks the beginning of life, cancer causes disruption to cells which results in them accelerating out of control.   It is seen as a disease of uncontrolled life and the boundaries between life and death are unrecognizable. The rogue cell originates within the body – it is "personified as deceptive as it hides and protects itself: it impersonates the subject long enough to establish the power of its real difference, often until it can overpower its host body" (Stacey 1997, p.78). By the time diagnosis occurs the cancer has established itself and has taken hold of the body.   It is easy to understand that for some, it is a grotesque disease because of its potential to cause damage through its ability to permeate bodily boundaries through mutilation and violation. Knowing that the cancer "hides inside instead, to protect itself until its roots prevent pragmatic amputation…it impersonates the subject often until it can overpower its host body" (bid).

The language used to describe cancer -- 'The Big C' -- creates a particular horror in the minds of people and the absent breast through mastectomy is perceived to be a violation of femininity. It is usually hidden and becomes a shameful event. As Stacey reminds us, the processes of women undergoing mastectomy and their post-operative care are designed to reaffirm and reproduce sexual and gender identities. Stacey suggests, "to keep one's femininity intact requires elaborate efforts…above all, energy should be directed into covering up the signs of this stigmatized disease and the effects of the treatment" (Stacey, 1997, p.71).

At the time of writing about her breast cancer, Spence stated 'The representation and politics of cancer remains a fairly taboo subject, except within the sensationalist media.' (Spence,1995, p.132) She situated her critique of the 'cancer industry' in the context of nutritional and self-help therapy research which she was able to pursue after leaving hospital. This included holistic attitudes although these were in their infancy during the early 1980's.

At a Women's Surgery Conference in Melbourne, Australia in 1990, Spence spoke openly about her conscious and unconscious history which she described as part of a healing process. She talked about her complex identity after breast cancer diagnosis – in hospital she was reduced to her disease, whilst outside the hospital she had a professional career, her friends and work colleagues and family. Spence began to challenge the boundaries between inside and out, private and public, personal and political. She looked at the way in which things pervade our culture and how this shapes our lives. Using her own photographs, feelings and bodily history, she challenged the taken-for-granted assumptions concerning public as against private. Examples of her emotional experiences are explored below.

1.4 Phenomenological accounts of living with breast cancer

In contrast to limited media and popular cultural representations of breast cancer, there is an important body of feminist work that draws on phenomenological approaches to explore the diversity and/or complexity of women's lived experiences. Stacey (1997, p.71) cites the experiences of academic Eve Kozofsky Sedgewick who draws attention to the rituals surrounding recovery. She states, 'with the proper toning exercise, make-up, wigs and a well-fitting prosthesis, we could feel just as feminine as we ever had and no one need ever know that anything had happened' (ibid). Women are offered a free wig service and prosthetics and more recently, reconstructive surgery. Everything is done to disguise the loss. Audre Lorde describes such an event in *The Cancer Journals*, where she was approached by a recovery visitor to the hospital bringing a pale pink prosthesis, to aid her recovery. The volunteers stated, 'you can look as good as you did before…nobody will ever know.' Lorde wondered whether there were any black lesbian feminists employed in the Reach for Recovery programme (Lorde 1988, p. 31).   Complete medicalization of the body leaves no room for personal feelings as Jo Spence discovered.

All too often, women are not allowed to address the 'other selves' which are ignored during the medical process. And as Spence reminds us, "If I don't find a

language to express and share my subjectivity, I am in danger of forgetting what I already know" (Spence, 1995, p.135). Her work is paramount in highlighting the importance of incorporating women's personal stories in social and political change. Her aim was to confront the notion of an 'idealized self' through her stories of disease and illness. Through this we become aware of the difficulty in finding a language in which we can express our ideas, emotions and personal knowledge's. The importance of continually finding ways of representing ourselves is further highlighted by Spence as she states:

> I didn't have the faintest idea when I first had cancer how to represent to myself what was happening. Finally I found a language for it. Now that I have leukemia, the language that worked with breast cancer doesn't seem applicable. This time around, I'm looking at it ecologically and globally and I have a totally different attitude to my body, my illness. (Spence, 1995, p. 215)

Both Stacey and Spence have shown us that biology is an open system which is fluid and dynamic. It is impossible to exclude the cultural and social. Furthermore, it is almost impossible to disentangle what is biological and what is cultural. Spence's reference to looking ecologically and globally seems to be saying that it is not just accepting that we get cancer but that we should be looking to the wider environment and to governments to focus on environmental pollutants which may be linked to cancers.[7] Rachael Carson's (1962) report acknowledged long after her death from breast cancer, provides evidence that pesticides may indirectly aid reproductive cancers by damaging the liver which is a key organ in maintaining hormone levels by breaking down estrogens and other hormones to aid their excretion. If as Carson suggests, women's biology is affected by certain pesticide and chemical exposures then this is problematic for females working in agriculture and factories across a range of production.

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[7] 'Following Carson, the authors state, strong toxicological evidence points to a large number of ubiquitous pollutants that are plausibly linked to breast cancer because they mimic or disrupt hormones known to affect breast cancer risk.' (Brody & Rudel, 2003, p. 1016).

Spence and others have brought together some of the more complex ideas about embodiment and experience showing how knowledge construction shapes women's thinking of health and illness and how they negotiate the biomedical world of breast cancer. The act of writing and reporting helps women make meaning in the construction of self: in the case of breast cancer it is the changed self. Promoting mutual support for women with mastectomies Lorde (1980, pp.61-64) encourages them to "become visible to each other… and translate the silence surrounding breast cancer into language and action against this scourge". Through writing and telling, we can move beyond the sense of alienation, the horror of mutilation as we look at the new image of self in the mirror. Some women can eventually move on, some do not move from the painful process of acknowledging the dislocated self as it becomes another bodily experience which has to be lived through.

Individual women have particular embodied identities. Removing one's breasts is seen as a threat to one's feminine bodily identity – one's femininity. In Western Society we objectify breasts as things to be looked at – as objects for the male gaze. It is not difficult therefore to see why reconstructive surgery is offered to women as a way of maintaining their 'natural' feminine bodily identity. The physical body from the outside may appear normal but on the inside she is walking around one breasted. Ucock (2002) illustrates this by examining how breast cancer survivors go through transformations of self in relation to bodily changes due to treatments such as radiation, chemotherapy or surgery. She analyzes various cancer discourses and interviews to study how the self is reconstituted after the effects of treatment which may result in hair loss, the removal of one or both breasts, physical impairment and how individuals "understand their appearance as a bodily experience rather than mere image or representation" (Ucock, 2002, p. 6). She states that appearance and self cannot be separated in the discourse of breast cancer survivors and argues "appearance is more than just an expression of self but it constitutes the self, or a part of self" (ibid). So many women experience loss of self after treatment for breast cancer. How we, and others, view our physical appearance is established during

childhood and sufferers find it difficult to integrate their altered outer bodies as part of themselves

Ucock's work informs contemporary feminist scholarship by recording the personal experiences of women with breast cancer, how they make meaning of the disease and the decisions they make regarding the transformation of their physical body. She explores the agency of women, how they engage in the production of their bodies and emphasizes that they are not just "cultural dupes" suckered by the ideologies of the 'cosmetic industry' and can resist the views of others in constructing their sense of self. She explores fear, disbelief, loneliness, loss, bodily appearance and social interaction in the diagnosis and transformations of self. She cites Merleau-Ponty (1976) who states that all human experience comes out of our bodily position; rather than just being an "object in the world" it is through our bodies that we come to understand ourselves and our relationship to the world (Merleau-Ponty, 1976, p. 5). The physical bodily changes that breast cancer creates, for example, the loss of hair and removal of the breast is added to the uncertainty of patient survival of the disease. A bald female will attract public attention whilst a bald male will not. These changes affect a woman's identity.

Victoria Brownworth's (2000) collection of stories, 'Coming out of Cancer', are about how women from the lesbian community are affected by cancer and their changed lives. She likens these experiences to "a hidden cell of women, just like the hidden cell of cancer. And just like the hidden cancer cell, can eradicate life, the memories of the hidden cell of lesbians with cancer could be eradicated if no one bore witness to their lives" (Brownworth, 2000, p.xiii). Her book focuses on sexuality and its intersection with race and class and "how this altered care and survival" (ibid). It is an historical document – a testament to both lesbianism and cancer status. Brownworth suggests that the story of cancer is like a "play, a stage production, a performance piece…cancer demands many roles: patient, martyr, heretic, lunatic, stoic, heroine, villain, saint, sinner" and many more (Brownworth, 2000, p,105). On the one hand, the performance will involve one

woman but inevitably it will be about many women. It is "never a singular take" (Brownworth, 2000, p.106) as it happens in several bodies over time and space for example, in "a dark lesbian bar…in Philadelphia in 1973" or in "a plastics factory in New Jersey in 1968" or it may have started in utero with the pregnant mother being exposed to the harmful carcinogens whose sources refuse to reveal themselves until it is too late. The "PCB's emitted from the liquid plastics pressing out the records sliding one after another onto a plate for eight hours at a time leaving fumes that won't wash off…" (Brownworth, 2000, p.107). The insidious nature of cancer is hard to source and the easiest way to resist it is "by denying its sources" (Brownworth, 2000, p.108).

Women's narrative research for some feminist writers, often include the researcher's auto/biography as Letherby (2003) suggests,

> …we draw on our own experiences to help us to understand those of our respondents. Thus, their lives are filtered through us and the filtered stories of our lives are present (whether we admit it or not) in our written accounts" (Cotterill and Letherby 1993, p.74).

Letherby (2003) states that the early work of Weber included personal involvement in his research and she refers to Mills (1959, p.204) who argues that "The social scientist is not some autonomous being standing outside society".

This locatedness embedded in women's lived experience in relation to race, gender and disability is illustrated by Felly Nkweto Simmonds (1999, p.50) who questions, "My body, myself: How does a black women do sociology?" By reflecting on her own experiences as a black one-breasted woman sociologist she challenges the privileged silence of whiteness and its taken for granted world. Here she cites Bourdieu and Wacquant (1992, p.127)

Social reality exists, so to speak, twice, in things and in minds, in fields and in habitus, outside and inside of agents. And when habitus encounters a social world of which it is the product, it is like a fish in water: It does not feel the weight of the water, and it takes the world about itself for granted.

But Simmonds cannot be this fish. She does feel the weight. The white world which she inhabits has constructed blackness as 'other' and inferior. She is a product of the social world – a white world which has a "problematic relationship with blackness" (Simmonds, 1999, p.50). Following Spivak (1993) Simmonds uses her embodied experience strategically, her body as "persistent (de) constructive critique of theory" and positions herself as a black woman academic in a white western institution in order to "explore the relationship between my body as a social construct and my experience of it" (Simmonds, 1999, p.52). In her cancer diary Simmonds writes "it is the loss of my right breast that has made me take account of the embodied experience in the making of social reality…on the outside I carry the same body; a fact and a fiction". Her breast cancer experience is part of the relationship between her embodied reality and her sociological practice (Simmonds, 1999, p.59). She warns of a continued racism if we remain disembodied theorists. She goes on to say that black experience written into sociology has to reveal private information (Simmonds, 1999, p.54) and states, "as a woman, as a black person, as an African, social theory has fed on my embodied experience" (ibid) through anthropology, history, art and photography, colonial narratives and so on.

Hall (2009, p.130) cites Rosemarie Garland-Thomson (quoted in Herndl 2002, p.154) who suggests that cultural rules are made about what disabled people should be and what they should do. Breasts on men are considered 'abnormal' in a two-sexed society and need to be surgically corrected just as the one-breasted woman after breast cancer is offered reconstructive implants to conform to female bodily norms although this can be seen to be resisted by many feminists particularly in the lesbian community – see for example Lorde (1980) who celebrated her asymmetrical body. However breast cancer patients view their missing breast or try to be positive in the management of their altered bodies,

there is always a reminder of the possibility of "recurrence of cancer in the remaining breast tissue" or metastasis (Thomas-MacLean, 2005, p.201).

In conclusion, this review of literature has highlighted the importance of incorporating women's narratives in social and political research. Their contribution to the questions raised in my research are important in three main areas: 1) knowledge construction – how women (re)construct their personal and social identities after breast cancer and how these contrast with biomedical models of health and illness, 2) It shows how our biology is more fluid and includes the cultural and social body, 3) it shines a light on how dominant ideologies of institutions and power relations impact women's health and work ability through disciplining and normalizing tendencies. The construction of knowledge and the workings of dominant ideologies are further outlined in the next chapter. It follows how breast cancer activism discursively engages the authorities and priorities of science and medicine and the workings of power within the breast cancer movement.

Chapter 2

The History of the Breast Cancer Movement and Ideologies of Health and Illness

This chapter follows the history of the breast cancer movement both in the UK and world-wide. It charts the development of how it evolved in America and how its ideologies were then transported to the UK and elsewhere. In her world-wide historical view of the breast cancer movement, Crompvoets (2006, p.67) explores how "gender and emotions are publicly mobilized and performed, how breast cancer activism discursively engages the authorities and priorities of science and medicine and the workings of power within breast cancer groups." Cancer charities play a major role in the UK in supporting cancer patients back to work. When patients are released from hospital they are encouraged to seek the support of cancer charities' health care teams who play an important part in patients' wellbeing and rehabilitation and more recently have influenced the RTW process (Macmillan et al 2009).

Smith (1987, p.54) states "…the class that rules the society by virtue of its domination…organizes, and sanctions the social relations that sustain its domination" therefore, it is necessary to direct our gaze to the production of cultural practices that are less visible within the relations of ruling. For example, we learn from Crompvoets' (2006) study how breast cancer organizations play a dominant role in persuading women how to think about their mastectomized body and she "challenges the hegemonic breast cancer identity they promote" (Crompvoets, 2006, pp 144-45). The author states that women have limited ways of making meaning about their illness experience and feminist scholars argue that biomedically defined accounts lack consideration of lived

experiences.[8] Few scholars have researched the breast cancer movement but Anglin (1997) used her own ethnographic experience to explore how treatment activism in the 1990's challenged the structures of power of science and medicine. King (2006) on the other hand, found "there has been a proliferation of academic and popular writing…in the United States since the early 1990'" which charts the development of how relationships between activism and medical management have changed, particularly since the start of the Susan G. Koman Foundation. This has certainly put breast cancer on the map according to Barbara Ehrenreich (Ehrenreich, in King 2006). However, it is not simply a matter of political organization during this time but as King suggests it is "because of an informal alliance of large corporations (particularly pharmaceutical companies, mammography equipment manufacturers, and cosmetics producers), [alongside] major cancer charities, the state, and the media that emerged at around the same time…to capitalize on growing public interest in the disease" (King, 2006, Introduction). The medical profession works closely with all the partners in the alliance. However, it is the informal practices of organizations and their support networks that are importantly linked to my last theme of work practices which involve how work place organizations perpetuate work cultures and practices. Just as employers have certain obligations and responsibilities for the wellbeing of their staff, this in turn extends into leisure and the quality of life outside the workplace. Many larger employers now encourage staff to fundraise for a dedicated charity or appoint a community champion to oversee activities within their corporations which I discuss in Chapter 7. In light of this, it is important to understand how breast cancer advocacy evolved.

According to King (2006) one of the most important dates in the calendar world-wide is breast cancer awareness month in October which was "founded in 1985

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[8] Crompvoets (2006:145) states "in women's narratives the post-surgical body is situated as a site of ambiguity and uncertainty…it has a lack of fit with dominant notions of how the mastectomized body should look and feel".

by Zeneca (now AstraZeneca), a multinational pharmaceutical corporation [and is a] most highly visible and familiar manifestation of this alliance" (King, 2006, pp xx-xxi).   It is perhaps easy to understand how breast cancer survivors are swept up in the emotion of the 'Race for the cure' carried out on a massive scale world-wide. Breast cancer survivors run for themselves or a family member or friend who has died of the disease. However, when you start to unpick the business intentions of the players in the field of this alliance which are hidden amongst the institutional structures of power, you discover, as King highlights, that Zeneca manufactures tamoxifen, which is the most commonly known drug for breast cancer, but also that, under its original auspices of ICI up until 2000, was "a leading producer of the carcinogenic herbicide acetochlor, as well as numerous chlorine and petroleum-based products that have been linked to breast cancer (ibid). The success of campaigns like AstraZeneca's are highly effective and continue as multi-million pound industries world-wide. As in the US, hundreds of UK organizations participate in 'Race for the Cure' events in October. The Pink ribbon is now symbolic of breast cancer. According to Crompvoets (2006, p.93) pink advocacy "produces a discourse on women's mastectomized bodies using feminizing and infantilizing tropes…[it] constructs the post-surgical body as desexualized, ugly and abnormal and necessitating concealment at all times" (ibid).

There have been some challenges to the powerful lobby of the breast cancer industry. For example, in the US, Breast Cancer Action's "Think before you Pink" campaign questioned Avon cosmetics about its fundraising practices i.e. spending money on "flashy and costly spectacles rather than channeling it directly to the causes" that participants want to support (Crompvoets, 2006, p.52). But spending on cancer research is relatively unchallenged and is supported by the public and by governments across all parties.

Leopold's (1999) book, *A Darker Ribbon: Breast Cancer, Women, and their Doctors in the Twentieth Century* highlights the power relations which exist between doctor and patient but also the wider social relations which impact on the lives of women with breast cancer. It is difficult to change dominant attitudes of powerful players in

the field. For example, the "prevailing biases in the research agenda reflect the influence of powerful interest groups…the scarcity of research into the role of man-made chemicals in cancer causation…is a result of active opposition of pharmaceutical and chemical industries to any research that might threaten or interfere with their operations" (Leopold, 1999, p.272).

The influence of powerful interest groups and dominant ideology is reflected in the work of Crompvoets (2006, p.86) who documented how a respondent who applied to become a consumer representative for an Australian breast cancer alliance, was refused a 'seat at the table' of the project because she posed a threat to the orthodoxy of the organization: she openly used the questionnaire to challenge the selection process and asked 'difficult' questions and so was cast from the mainstream breast cancer community.

These studies show how large-scale charity events promote fundraising events on a massive scale which constantly engage public and media interest and enable the breast cancer movement to mobilize certain meanings and understanding of breast cancer experiences. Pink advocacy is a way of repairing the body beautiful by perpetuating a "homogenous response to breast loss and provides limited space for women to consider alternative mechanisms with which to reconceptualize the changed landscapes of their post-surgical bodies" (Crompvoets, 2006, p.146).

2.1 The Role of Cancer Charities in Supporting Government Health Initiatives

This section explores how mainstream cancer charities in the UK partner government agencies in supporting health initiatives. The charities' literature is given freely to cancer patients as they exit the consultant's room after diagnosis. Recently, cancer charities have partnered with other organizations in publishing

reports on cancer and work. For example, Macmillan and The Scottish Centre for Healthy Working Lives (2009) produced a DVD and booklet resource pack. On the front page they feature Bupa Foundation, The Medical Research Charity naming their award for excellence in Occupational Medicine 2007. This resource offers generic information: case studies of cancer survivors working in various occupations, cancer treatments, legislation and what it all costs. It offers an index of useful organizations for employers and employees at the end of the pack, listing contact details of other mainstream cancer charities.

In 2009 Macmillan also partnered the Citizens Advice Bureau to produce a report "Failed by the System" to show why the Employment and Support Allowance isn't working for people living with cancer, again using case studies to illustrate how government legislation and policy impact working lives after cancer. There is a list of recommendations to the Department of Work and Pensions (DWP) regarding the need for better communication between other state offices, i.e. Pension, Disability and Carers' Service and Job centres, so that claims are handled more efficiently thus avoiding distress caused to terminally ill people. They refer to better training of staff in these agencies, stating that medical assessors should be equipped to ask the 'right' questions about claimants' cancer treatments. The report highlights the need for better support for cancer patients and asks the DWP to "change the rules for people who have been diagnosed with cancer but have not started treatment" to enable this group to be supported "until their treatment regime and timings have been confirmed" (Macmillan, 2009, p.11). I return to address these difficulties experienced by claimants with breast cancer in Chapter 6. This information is reiterated in another report by Macmillan "Making it work" (2009) emphasizing that it is the responsibility of the DWP to help and support cancer patients to remain in work. This report also refers to economic modelling commissioned by Macmillan[9] which shows that if just half of the breast cancer survivors who initially return to work

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[9] See the report "Demonstrating the Economic Value of Co-ordinated Cancer Services: An examination of resource utilisCancer_care_research/MonitorResearchingManchester-costeffectivecare.aspx

but then leave were helped to stay in work, the economy could save £30 million every year".

In 2006 Cancerbackup in collaboration with CIPD and the Working with Cancer group produced a policy document, "Cancer and Working Guidelines for Employers, HR and Line Managers" in response to a survey which explored whether work place policies were meeting the needs of people working with cancer which they circulated on-line to CIPD membership. The responses based on 219 organizations employing more than 800,000 employees, showed a high demand for information and guidance that could be used by employers, employees, co-workers and carers. The findings were alarming: 73% of employers did not have a formal policy in place for managing cancer; although 80% of respondents were aware that the DDA now classes cancer as a disability, 20% of employers were not aware of this; only one third of organizations ensure that staff have a good understanding of how cancer impacts work; only 14% of organizations track cancer in the workplace and a third do not have records to show a RTW. A third of organizations provide or pay for counselling services and half of employers purchased private medical insurance for some categories of employees- within these, only 9% assess the suitability of their cancer related cover. More than 40% said their organizations present no information or support to employees with cancer – 36% were not aware whether they did or not. This report provides useful guidelines for employers to use, from first steps meeting with cancer patients through to maintaining employee involvement and engagement and their eventual RTW.

In the context of these reports we need to ask: what are the limitations of only looking at the financial cost of sickness absence and what is left out of the discussion as a result? Are breast cancer patients seen as a 'risk' and present a threat to productivity? The fact that breast cancer is increasing year on year, means that it is important that patients are represented fairly both by employers and health professionals who must take into consideration the wider social contexts of their disease. According to Nilsson et al (2013, p. 2757),

Having low work adjustment and/or less perceived social support from supervisors were positively associated with Sickness Absence early after breast cancer surgery.

In their report *Making the shift; providing specialist work to support people with cancer* Macmillan (2013) reiterate what was said in their previous research but this report calls "for health and work departments to 'make a shift' in their thinking and take responsibility for improving access to vocational rehabilitation in the UK" (Macmillan, 2013, p. 4). Their message challenges government's response to the sickness absence review saying that "it does not consider the role of secondary healthcare, including NHS rehabilitation services…at how the NHS could be incentivized to view the return to work of people with long-term conditions as a positive health outcome" (Macmillan, 2013, p.6). Macmillan's arguments are similar to all other intervention models, suggesting it benefits people living with cancer and the economy. Again, they stress that getting people back to work after cancer improves productivity and the "loss to the economy is likely to increase, with the number of people living with cancer in the UK set to double from two million to four million by 2030" (Macmillan, 2013, p.8). In this report their model of vocational rehabilitation services for people with cancer - tested in seven pilot sites in the UK, offers slightly more detail than in previous reports. Level 1 is fairly straightforward as it is about information and signposting. However, Level 2 could present problems for breast cancer patients who would be offered "resources to help [them] self-manage so they can return to work" Macmillan, 2013, p.12). Self-management may appear to be quite straightforward given the tools to deal with your problems but what if the wider social institutions of ruling are not playing their part? Who is speaking out for women with breast cancer in the workplace who are on agency or zero hours contracts? Although it is important that patients are involved in their recovery process it could also place responsibility on the patient to cope with her problems at work whilst having to deal with the after-effects of treatment.

2.2 Public and Patient Involvement and Government Health Reforms

Following The National Institute of Clinical Excellence (NICE) guidelines, David Cameron's Conservative Government proposed that changes be made to the NHS which 'puts patients first'. This involved creating a system grounded in patient involvement and shared decisions made by various stakeholders that would become the norm. There is a core distinction to be made here between public involvement, which involves essential cancer services, their legitimacy and accountability as opposed to individual patient's involvement in their health care. NICE stressed the importance of a commitment to patients, service users, carers and public involvement and produces guidance for the NHS. [10] In 2013 NICE recommended local advisory committees should be set up and have at least two lay members (patients, service users, carers or member of the public" This patient-focused initiative would include public health needs of specific groups and communities with the aim of being open and transparent. This devolution of power is a direct response to tackling the increasing health inequalities over the past few decades.[11] It is important to know how these reforms will be rolled out locally and how they will impact on the increasing numbers of women who develop breast cancer each year.

As part of the public involvement proposed by the government there have been some initiatives in developing these services. The Health and Social Care Act 2012 created new statutory duties on all NHS organizations in England providing publicly funded health and social care services in order to engage patients and the public in the development and delivery of services. An example of how local user involvement could work was presented by Tritter (2004). He devised a toolkit to help develop user involvement in cancer services which was derived from the experiences of collaboration over some years between stakeholders within the Avon, Somerset and Wiltshire cancer network. The network enlisted help from

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[10] NICE quality standards are a set of specific concise statements that act as markers of high-quality, cost-effective patient care, covering the treatment and prevention of different diseases and conditions.

[11] DH (1997) a press release was issued announcing that a Public Health Strategy would be launched into the root causes of ill-health.

two universities and two charities. [12] The aim of the toolkit would be a model which could be used for all cancer networks regionally to improve quality of cancer services. However, in 2010 Tritter found measurement and evaluation difficulties in piloting a public and patient initiative (PPI). A Performance Management Evaluation of a framework in Northern Ireland which was paralleled in England in 2010, highlighted different dimensions in organizational structures and processes and how decisions were influenced and the impact on stakeholders. Tritter found difficulty in getting clinicians to buy-in to PPI but stresses that getting involved should be seen as a process which we go through and learn from (ibid). Furthermore, he stressed that we need to measure outcomes realistically because the cost of evaluation leaves less to be spent supporting social care. Tritter currently calls for more evidence based involvement in order to make a case for PPI.

If as NICE recommends, all advisory committees and working groups will have at least two lay members (patients, service users, carers or member of the public) (NICE, Nov, 2013) legitimacy and accountability issues still remain. There are questions about how these groups are formed and how their members are recruited. Are cancer charities, outside of mainstream users, invited to apply to join the advisory committees? There is evidence of involvement from the three larger cancer charities: Cancer Research UK whose interests involve scientific researchers, pharmaceutical companies and medical doctors who advise the government about what should be included in the national cancer plan; Cancerbackup[13] who has recently established working guidelines for Employers, HR and Line Managers in partnership with the Chartered Institute of Personnel and Development (CIPD) and lastly Macmillan Cancer Support who provide,

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[12] Collaborative partners included University of the West of England, University of Warwick, Avon, Somerset and Wiltshire Cancer Services and Macmillan Cancer Care.

[13] Cancerbackup, WWC and CIPD carried out a survey in 2006 to determine how far workplace employment policies met the needs of cancer patients. The results showed there was a demand for both policies and information for results.

http://www.cipd.co.uk/pm/peoplemanagement/b/weblog/archive/2013/01/29/sufferinginsilence-2006-10.aspx

amongst many other services, training workshops in conjunction with the TUC for union reps and members around issues of working with cancer. These three main national cancer charities attract vast amounts of funding, working with scientists and health professionals. They are respected and accepted by government and the public and retain powerful platforms in decision-making compared to smaller cancer charities[14] who may work under the wider umbrella of social and environmental models of health and whose interests may conflict with the dominant bio-medical model. Those who become registered stakeholders to inform the scope and development of NICE guidance, it seems, are those who hold the balance of power. These power relations are also at work through media and cultural discourses which I have discussed in the previous chapter.

2.3 The NHS Plans

The NHS Five Year Forward View (2014:11) states there needs to be:

> NHS support to help people get and stay in employment. Sickness absence related costs to employers and tax-payers have been estimated at £22 billion a year, and over 300,000 people each year take up health–related benefits.

This NHS report, alongside academic studies, agree that there is a need to keep people in work thus "improving their wellbeing and preserving their livelihoods". I return to the topic of wellbeing in chapter 7. In their report, *Health at work – an independent review of sickness absence,* (2011) Carol Black and David Frost recommended to Government that "employers provide financial support for

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[14] The Alliance for Cancer Prevention whose members include: Trade Unions, European Chemical Health Researchers, Occupational Health professionals, Environmental groups, Civil Society and Women's Health groups. See also The Hazard Campaign actively works with the TUC to ensure Health and Safety standards are applied.

vocational rehabilitation services without employees facing a tax bill" (ibid) although it seems that this is left to the discretion of different employers and how they manage sickness absence which I discuss in more detail in Chapter 6..

In a report by the Independent Cancer Taskforce entitled *Achieving World-class Cancer Outcomes: A strategy for England 2015-2020* it was stated:

> Macmillan Cancer Support and other charities have worked with a number of local authorities and employers to pilot schemes which assist people who have had cancer in returning to work. Return to work plans need to be fully integrated into care planning to encourage the commissioning of vocational rehabilitation services (p.60)

In this report they anticipate that care be placed in an "appropriate time frame, written and agreed by a multi-disciplinary team" and that the model provides "Patient centred care…that is respectful of and responsive to individual patients" (p.83). The report lists mainly clinical studies and representatives who act as advisers on mainstream health, for example, Macmillan and Cancer Research UK. There is only one study listed that refers to social issues around work and cancer which is a study by de-Boer (2009) on cancer survivors and unemployment [15] but this study focuses on intervention strategies and does not explore the reasons why some women do not return.

The Taskforce report discusses living with and beyond cancer and states: "Care should be built around what matters to the person" and they should be "equipped to manage their care and with control over their life as a whole" (p54). Furthermore,

> as well as the financial and social benefits of being in work, there is strong evidence that good work has a positive impact on people's health and recovery. However, people with cancer are currently 1.4 times more likely

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[15] See de Boer, A.M., et al., Cancer survivors and unemployment: A meta-analysis and meta-regression. JAMA, 2009. 301(7): p. 753-762.

to be unemployed than the general population and many struggle with little or no co-ordinated support to remain in work following treatment (p.60)

If work is important to patients living with cancer and care should be built around 'what matters' as the report suggests, then women with breast cancer need to be able to access various resources that enhance their return, resources not only within their workplace but also outside in the form of integrated cancer alliances through provision of care in their immediate communities. However, the report warns these integrated services need to be better monitored:

> Current commissioning arrangement combined with tightening budgets, have led to fragmentation and a loss of momentum in transforming cancer services. There has been a loss of local leadership and infrastructure, leading to variation across organizations in their approach. We need to build relationships and inject cancer-specific resources and expertise into local health economies and redesign the accountability framework (p.62).

As part of these alliances, there is evidence to suggest that Macmillan play an important role in supporting breast cancer patients back to work post diagnosis and treatment (see chapter 7, patient's blog by Sonjajo, 5 Nov, 2015). However, problems still exist for many women during the transition of leaving the safe confines of Macmillan hospital based care, being signed off as 'fit for work' and entering the workplace where support becomes the responsibility of the employer as my research shows (see chapters 6 and 7).

Government departments are entrusted to advise on legislation affecting economic and social reform which become part of the ruling relations that impact our society. These rulings are effected by organizations. One such ruling is the Fit for Work Guidance for Employers 2014 written by the Department for Work and Pensions that purports to provide additional support for those in employment at risk of long term incapacity. This guide identifies barriers for returning, and sets out detailed information about return to work plans, work adjustments, signposting to other useful services and information (DWP, 2014, p.12). I return to discuss barriers to RTW experienced by benefit claimants, Shirley and Janette in chapter 6. The guide also provides information about reducing sickness

absence costs by encouraging employees back to work more quickly and tells the employer how to get access to independent specialist help on occupational health assessment for their employees and adjustments that need to be made. This guide is designed to support employers, employees and GPs with steps to be taken to support a return to work and limit reoccurring sickness absence (p13).

The Taskforce report stresses that patients and the public (supported by charities) should provide external accountability to ensure higher standards and delivery but how can this be monitored in the workplace and by whom? Charity bloggers are already suggesting – (see Rupert66 below), that employers will put business ahead of the individual. If this is the case then it is problematic for women returning to work after breast cancer who might be feeling vulnerable and who are in precarious work contracts (zero hours), afraid to speak out for fear of losing their jobs after a long sickness absence. This is when legislation fails to protect them. The report also states that Macmillan and other charities have worked with a number of local authorities and employers to pilot schemes to assist cancer patients returning to work. When I approached Macmillan asking for a copy of such studies, they stated they had not carried out research and advised,

> I'm afraid the way the Cancer Strategy describes this work is a bit misleading. This was not research carried out by Macmillan. It is rather a service offering resources and training to employers in the public and private sector (email: evidence@macmillan.org.uk sent 6 Nov 2015 9:24).

The above information raises many questions and concerns about working with cancer. It also highlights two main problems here. Firstly, some women have difficulties in accessing support to remain in work after treatment and secondly, charities like Macmillan alone will not be able to monitor how employers may flout the law as they have reported. The Taskforce report states that current commissioning services are not working – if they have become 'fragmented' in their present state, then who will take responsibility to monitor how cancer services will be run? If some Clinical Commissioning Groups (CCG's) are more efficient than others because they prioritize cancer-care and have support

services in place as opposed to other trusts who do not, are we moving towards a more 'post-code lottery' style of cancer care management where class and ethnicity could affect our survival. If commissioning services are 'fragmented' then how can employers take a lead on managing cancer in the workplace?

In 2011, Macmillan in association with CIPD updated information for employers which they included in The Essential Work and Cancer Toolkit pack (Macmillan, 2011), an on-line resource offering practical advice (and training) on managing cancer in the workplace. Both of these organizations offer a way for managers to set up a working procedure for cancer patients under The Equality Act 2010. However, my research found that Local South West employers had not come across these documents (see Chapter 7). This raises a bigger picture about the new relationships between the state, charities and employers around managing employee health and how this impacts workers with cancer. The question must be asked: how is this tri-partite relationship between state, charities and employers joined up. How do charities reach employers in order to monitor how working with cancer is managed? Does every HR department visit these charity websites to see what is on offer? Some employers decide to outsource the management of the health and wellbeing of their workers to private companies which could be argued, distances them from working with cancer and lessens their responsibility to ensure that these employees are not discriminated against because of their cancer which I discuss in chapter 7. This chapter has looked at government health initiatives and explored the role that cancer charities and government departments play in supporting these.

Chapter 3

Empirical Studies on breast cancer experiences and a return to work

3.1 Introduction

The studies discussed below are the key scholarly research studies about women's breast cancer experience and their RTW. I am structuring the discussion of the literature around three themes which emerge in the scholarship and which are relevant to my research questions.

3.2 Main themes of my research

The first theme is about **knowledge construction** which is situated around breast cancer diagnosis. It examines how women construct knowledge of the disease; normalizing and body image; treatment options and how they are supported by health professionals who help them prepare for RTW. Feminist scholars have documented how the construction of knowledge is dominated by biomedical frameworks which fail to address the lived experiences of women with breast cancer[16] (Crompvoets, 2006, p.58). Issues of embodiment around breast cancer involve more than simply attending work again. Some women continue to struggle with the effects of breast cancer long after surgery and treatment. For example, the mastectomized body and/or the development of lymphedema force women to adopt new identities and behaviours, both at work and at home. Manderson and Stirling, (2007) (Australia) and Chun and O'Connor, (2011) (Canada) use discourse analysis and gender-based analysis to frame women's

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[16] Crompvoets draws on Fosket, (2000) to show how the biomedical model limits how women make sense of their illness; Rosenbaum and Roos, (2000) identify three areas of meaning from women's stories, 1) perceptions about disease 2) treatments compromising identity and 3) how breast cancer is hidden away; and Thorne and Murray, (2000) suggest how construction of breast cancer arises from historical and cultural contexts.

experiences of breast loss and lymphedema whilst Thomas-Maclean (2005, 2008) (Canada) adopts an extremely useful multidisciplinary approach in the study of life after breast cancer and what it means to be embodied, using feminist and phenomenological methods of data collection. Crompvoets (2006) (Australia) also provides an insightful view of recovering the self after breast cancer. Although these four studies are not focused on RTW, they usefully inform my research question on how women construct personal narratives of the disease in relation to the dominant medical models which I discuss in the next section.

My second theme focuses on women's **return to work** which involves issues around work-ability, physical and/or mental impairment, phased return/work adjustments, and coping and not coping. Here the literature is scarce and suggests that there are gaps to be filled. Johnsson et al (2010) highlight the need for better social support in the workplace, clearer management and work roles which they say are factors associated with psychological health and well-being. I aim to fill these gaps by examining discourses around workplace practices which I discuss in the last section. The focus on how women see working with breast cancer is easily ignored in most clinical research carried out on women's RTW after breast cancer. Here the focus is on intervention strategies for the purposes of insurance and the management of long term sickness. But there appears to be minimal evidence to show how these strategies support the patients themselves in their recovery. However, the following studies shed some light on how this type of study would be useful where private medical insurance is in place. For instance, in contrast to the UK's National Health Service and benefits system, other countries have private health insurance tied to employers intervention strategies that get women back to work quickly after breast cancer, eradicating long term sick pay through employer's insurance schemes.

My last theme, **Work Practices** involves issues around employment contracts, career and career changes, redundancy, discrimination, fairness, employer support, informal practices, organizational culture, obligations and pressures,

financial issues, quality of life and standard of living for which family and other support networks such as cancer support groups play a large part. The following studies shed some light on the issues arising in my research and possible further research that could be built on some of the findings.

3.2.1 Approaches to the construction of knowledge in the study of breast cancer

Thomas-Maclean (2005, p.201) considers how feminist approaches to data collection and analysis can help develop new understandings about breast cancer care. She adopts a "multidisciplinary approach to understanding breast cancer" namely one that directs attention to social context and an in-depth exploration of the meaning of embodiment for women, and one that could enhance understanding of breast cancer experiences. Accordingly, there are a number of life-altering factors that a woman must reflect on after breast cancer. Following Olesen (1992)[17] the author highlights the importance of knowing that embodiment is about immediate experiences located in a specific context which could apply to any study on RTW but also useful in examining the body's intersection with culture. She cites Bredin (1999) who explores the breast's "symbolic and physical association with being a woman" (Thomas-Maclean, 2005, p.201). [18] She discusses how some women feel they need to remain attractive to men which seems to dominate the psychiatric and psychological literature on breast loss and illustrates the dominance of 'patriarchal appearance norms' (ibid) but their decisions about mastectomy outweigh breast conservation because of the fear of recurrence. The three key themes in Thomas-Maclean's study: breast loss, managing appearance and treatments without end are relevant to my first research theme as this explores how it feels to lose a breast,

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[17] For further information on this model see Olesen N.L. (1992) Feminisms and Models of Qualitative Research. In The Landscape of Qualitative Research, eds NK Denzin and Y Lincoln, 300-32 Thousand Oaks, CA, Sage.

[18] See also the work of Bredin (1999), Kasper (1994) and Young (1992) the few studies that directly connect individual experiences and the social context of breast cancer.

how women manage their appearance – whether they wear a prosthesis or not and their on-going treatments. She states,

> Survivorship is a dynamic, life-long process, which suggests that health professionals can play an important role in establishing interdisciplinary approaches to caring, beyond the conclusion of acute treatment (Thomas-Maclean, 2005, p.200).

Although this appears to support intervention strategies by health professionals it is also acknowledging the need to adopt a multidisciplinary approach to exploring health and is "rooted in a feminist perspective, which explores the intersection of body, society, biomedical perspectives and social forces, or embodiment" (ibid) and how this affects everyday life. Citing Bredin (1999) the author strongly emphasizes how scholarly work on breast cancer fails to address dimensions of power and how inequality impacts women living with breast cancer which my research aims to address. Her focus on embodiment arose from previous work situated in the sociology of health and illness which also informed my research project. The data from a focus group of breast cancer survivors was used to facilitate the development of her interview guide and she subsequently interviewed twelve respondents. Following feminist scholars (Olesen 1992; Bentz and Shapiro 1998; DeVault 1990) she carried out a close reading of the transcripts to explore "ways in which participants' experiences were illustrative of the particular social context" which includes how women's breasts were featured in popular culture. She skillfully weaves together her findings with the relevant literature such as Wendell's (1996, p.85) work on the rejected body and also how embodiment is both actual or imagined through others. [19] This illustrates the importance of management and bodily appearance after treatment for breast cancer which should be "recognized as constituents of the disruption of ability associated with illness" (Thomas-Maclean, 2005, p.203). For example, she draws attention to bodily changes in one respondent reporting that "difficulties

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[19] See Wendell (1996) *The rejected Body: Feminist philosophical reflections on disability.*
and Toombs (1995) *The Lived Experience of Disability.*

with arm function were more traumatic than breast loss" as the breast was hidden but the arm was visible to the public (Thomas-Maclean, 2005, p.207). The issues raised by Thomas-Maclean could usefully be extended and placed in the whole context of women's RTW. We need to ask how easy it is for women to discuss work-ability and the many other physical and psychological problems of breast cancer 'treatments without end' with their employers without facing discrimination or fear of job loss.

Chun and O'Connor (2011, p.113) highlight the importance of Thomas-Maclean's (2005) statement that "women who undergo breast cancer treatments continue to struggle with its effects long after the operation". Following Brown's (1995) model of framing disease and illness they use open-ended interviews to allow respondents to talk freely about their perceptions and experiences of breast cancer. A brief questionnaire was administered prior to interview, which gathered data on both general and disease characteristics similar to Tamminga (2012). Applying a gender-based analysis to the whole project allowed the research to focus on constructions of health and wellbeing and how women's perceptions and experiences are situated within the understanding of this condition. The idea was not to arrive at a single conclusion but to explore the many varied experiences of the women with the same condition which will be an important feature in my research analysis. The authors report that their findings do not represent "definitive and fixed aspects of participants' lives; rather they demonstrate the diverse and complex ways in which women perceive and experience lymphedema at particular times in their lives" (Chun and O'Connor (2011, p.117). It depended on the different ways in which they managed the condition which is further impacted by other variables such as class, race, ethnicity, sexuality and disability which stem from wider "systems of social, cultural and economic interactions" (Chun and O'Connor, 2011, p.118). Two principal themes emerged from the data, body image and changes in quality of life. In the first, the authors refer to Pitt (2004) who argues that some women try to hide signs of illness because it relates to the accepted "norms of femininity and beauty… rooted in patriarchal constructions of gender" (ibid). The authors draw

on feminist theory to explain why the women feel the way they do about breast removal, scarring and swollen arms and describe how images of sexuality and motherhood "negate alternative appearances of women's bodies" (ibid).

Like Thomas-Maclean's (2005) study, Chun and O'Connor (2011) explore some of the underlying problems that women with lymphedema face, such as arm movement which may affect their workability which is particularly relevant to my respondents returning to work with this disability. For this group of women it means that there is an accumulation of lymphatic fluid in the subcutaneous tissues and this can have a significant impact on their physical and psychological health in terms of body image and work ability. Overall, it can affect one's quality of life (QOL)[20]. The authors remind us that one in eight women will be diagnosed with breast cancer at some-time in their lives and lymphedema can develop at any time after breast surgery sometimes even years after. There is no cure for lymphedema and there are limited treatments to manage symptoms. This raises issues for women's RTW and how employers address disability and work performance. It highlights the need for employers to understand fully the problems that women face with this condition on their RTW. These are issues centred around my third theme of work practices. The authors stress that existing research into lymphedema focuses on "scientific aspects of the disease, the effectiveness of treatments, and measurements of QOL…through mobility measurements" (Chun and O'Connor, 2011). Drawing on the work of Karadibak et al (2008) and Ridner (2005) the authors highlight that lymphedema patients experience greater levels of bodily impairment than other breast cancer patients. They also suffer poorer mental health and increased anxiety levels.

Framing lymphedema using Brown's (1995) model works very well in addressing the social construction of illness. This theoretical framework positions illness and disease in a wider social context. It separates disease and illness: disease is a

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[20] See also (Vignes et al., 2007; Karadibak, Yavuzsen, & Saydam, 2008).

concrete biomedical condition diagnosed by medical professionals whereas illness is associated with the patient's own experience of disease. Brown uses four stages. Firstly, the disease is identified. Secondly, the patient experiences the disease. Thirdly, the patient is treated and lastly, there is an outcome of the treatment. This is important in addressing power relations highlighting how physicians are differently placed to patients. It explains how the "physician deals with the disease as a separate biomedical entity" whilst allowing the patient to voice their lay opinion about their experiences of illness. (Chun and O'Connor, 2011, p.115).

Chun and O'Connor go some way to show how lymphedema affects their respondents' quality of life, how they had to made adjustments to their role as housewives and in their paid employment. One respondent reported not being able to work more than a day without having to take the next off and that these issues were not understood and addressed by health professionals. Although Chun and O'Connor (2011) use only the second stage of Brown's four stage theory i.e. the experience of illness, they are aware that "experience and illness can never fully be separated from elements of clinical interaction…they form a strong basis for people's understanding of illness which in turn, influences diagnosis and treatment" (Chun and O'Connor,2011, p.122). An important finding was that the respondents were determined to manage their lymphedema but needed help from "support networks and advice from physiotherapists and cancer support groups. Breast Cancer Action, the author's community partner for research, advised of the benefits of networks shared with other women for friendships and common bonds although some considered there was a lack of such support (Chun and O'Connor, 2011, p.123). My first theme seeks to address the role of support from health professional in the RTW process. Overall, body image was a significant factor found to affect women in their everyday life "adding an additional level of stress to the physical impacts of symptoms" and "affected the roles with which women identified themselves" (ibid) and this includes their work roles.

Mandelson and Stirling (2007) offer a useful insight into how Australian women talk about their mastectomized bodies from different perspectives within different discourses: medical, sexual and material. They conducted interviews with twenty women, over multiple sessions to gain patients' full accounts of their illness experience. Questionnaires were sent out prior to interview. The researchers used a narrative guide with open-ended questions to allow the respondents to talk about significant events and to enable them to make sense of their experiences.

They raise important questions about identity such as, "what is the part of the body left after a mastectomy? (Manderson and Stirling, 2007, p.75) and use discourse analysis to interpret the narratives of women as they describe the decisions that they have to face about radical v conservative surgery and treatment options which are further complicated by the trauma of the diagnosis of breast cancer. In this study women talk about mastectomy using passive descriptions such as 'taken' or 'removed' to describe loss of their breasts or act as they have been robbed, by saying that "they took my breast off" (Manderson and Stirling, 2007, p.83). This type of passive construction is used by many women it seems, including some respondents in my research. Sometimes the language is more violent with terms like invasive and aggressive coming from a medical frame of reference to describe the type of cancer. Cancer metaphors are commonly used both by cancer charity campaign slogans such as "we will fight cancer together" (Cancer Research UK) and also by health professionals to encourage patients to focus on 'fighting the enemy' which refers to cancer cells whilst they are going through chemotherapy, "an enemy that must be battled" (ibid). On hearing the biological explanation from the surgeon, especially if the cancer is a late stage, then the women has no option but to place her body in the hands of the surgeon. The authors cite Langellier and Sullivan (1998, p.79) who found their respondents "used the noun *breast* rather than…speak of their breast(s) as 'me', or spoke illusively of 'it'" which is formal speech used in this more "seriousness of the disease…" which is in contrast to how the media report on a women having cosmetic surgery which they refer to as having a 'boob job'

(Manderson and Sterling 2007, p.85). The authors also cite the work of Hartman (2004)[21] who states "women poets have written about breast cancer in ways that push illness into new avenues of meaning". Some women disassociate themselves from their body, "The body is and is not the self" (ibid, p.87) which is how some patients cope with long term illness and chronic pain.

Manderson and Sterling (2007) state that these personal experiences are coming through, not from medical/scientific literature but more frequently from humanities and the social science literature. They suggest there are no scholarly accounts of how women "talk about their breasts when they are no longer there" (Manderson and Sterling, 2007, p.76). This study focuses on how women adapt to their changing bodies after surgery and how "establishing a sense of normalcy, helps each person integrate corporeal change into their own (positive) self-image" (Manderson and Sterling, 2007, p.77).

A vital component in my research was to understand both the workings of the dominant medical model which claims to be purely objective[22] and how 'institutional ruling' may impact the working lives of women with breast cancer. The medical text which uses technical language, distances itself from the subject they are writing about and often makes assumptions about how women make sense of their disease and have traditionally been about cancer within medical disciplines, "decision making, coping mechanisms, and risk assessment and management" (ibid) which comes across clearly in the studies whose main theme is intervention.

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[21] See Hartman, S. (2004) *Reading the Scar in Breast Cancer Poetry*, Feminist Studies 30(1):155-77.

[22] Crompvoets (2005) claims Biomedical knowledge both derives from and aligns with science in order to bolster it legitimacy. This also follows Bourdieu's notions on reinforcing structure of power.

The above authors have all made important contributions to knowledge on breast cancer and the post-surgical body. Crompvoets (2005) discusses a range of approaches from femininity, gender and embodiment – being a body and having a body. Focusing on language as discourse, she looks at how language is constructed which has usefully informed my first theme. She describes how the use of medical metaphors remove women's bodies from reality and suggests the post-surgical body is performed in many ways. (Crompvoets, 2006, pp18-22). These contributions have provided an insight into embodied experiences which could readily be extended into other social contexts as they have done in my study of women's RTW after breast cancer. If one in eight women will experience breast cancer some time in their lives and 28% develop upper-body lymphedema as Chun and O'Connor (2011) question, what does this mean for their future employment? Will it add to the precariousness of employment opportunities for women? My research aims to explore how different women with different types and stages of breast cancer deal with these 'unspoken' problems and how they navigate the invisible structures of power on their RTW. But first we must establish what are these structures of power and who holds the balance of power in constructing knowledge and in making decisions for women with breast cancer. I will discuss this in my last section around the theme of work practices. Now, I explore studies that have been carried out on RTW after breast cancer but which have a particularly focus on intervention. I discuss how they relate to my project and in the final section, discuss how I can build on their findings in my project or future research.

3.2.2 Return to work

For Tamminga (2012) two models form her theoretical approaches that address adverse work outcomes affecting cancer patients: the International Classification of Functioning (ICF) set out by the World Health Organization (WHO) and the shared-care model for cancer survivor care. Tamminga refers to the fact that the "ICF provides clarification for the findings that both personal factors (e.g. self-assessed work ability), and environmental factors (e.g. work demands) are an important prognostic for whether patients return to work" (Tamminga, 2012,

p.13). This classification "allows a comprehensive analysis of the factors influencing RTW" (Tamminga, 2012, p.51) but although she briefly notes these as environmental factors, there is no analysis of social and cultural aspects of either workplace-policy and practices - my research aims to explore these blind-spots.

The author conducted twelve face-to-face, semi-structured interviews with breast cancer patients in the Netherlands with the objective to identify, 1) factors experienced as barriers to and facilitators of the return-to-work (RTW) process, 2) which factors were important during initial and post RTW, and 3) possible solutions to RTW problems. In addition to this, a case study was carried out to test a hospital-based work support intervention scheme to evaluate support for cancer patients' RTW. The case study found "the nurses helped the patient to resume work gradually…improved communication with the occupational physician…resulted in the patient being able to achieve lasting return to work" (Tamminga, 2012, p.220) but the research does not detail the lasting return to work. Tamminga found RTW "rates were generally high" although she found "non-statistically significant findings between groups" i.e. the intervention and the control group (Tamminga, 2012, p.222). Her recommendations are for further study to assess which aspects of intervention are useful. Overall, I found this PhD thesis a useful introduction when reviewing the scholarly literature. It goes some way in helping to understand what factors facilitate and what are the barriers returning to work for breast cancer patients. However, I would want to explore what structural changes could be made to determine how policy is put into practice by employers – i.e. what were the changes to workplace disciplines and practices? This could then enlighten the whole process of intervention.

There are similar themes running through all the European studies that advocate intervention. However, these emanate from clinical/insurance management

departments [23] but predominantly the studies all support Tamminga's (2012) findings and identify certain barriers to RTW. For example, on the part of the employer, Gudbergsson et al (2009) (Norway) advocate that supervisors need to play more of a supporting role in the workplace and Kennedy et al (2007) (UK) state that there is a culture of ignorance within organizations. In terms of work ability, Kärki et al (2005) (Finland) state that there is a need to develop systematic rehabilitation protocols specific to breast cancer patients and Hoving et al (2009) (UK) state rehabilitation programmes need to be of adequate duration, frequency and intensity. Additionally, Hubbard et al (2013) (UK) call for more effective vocational rehabilitation intervention trials.

In terms of work ability, Tiedtke et al (2012) (Belgium) report vulnerability and poor mental and physical preparation for RTW and Munir et al (2010) (UK) state that cognitive functioning affects manual and non-manual jobs. Banning (2011) (UK) suggests that health care professionals should offer better support to employers to help breast cancer patients RTW. In terms of age, Adams et al (2010) (UK) emphasize the necessity of applying a conceptual model for young women (of reproductive age) with breast cancer which may have significant meaning considering the younger age groups of women developing breast cancer. Palmadottir (2010) (Iceland) suggests there is a need to explore new occupational possibilities in illness by broadening approaches and participation in creative therapy for wellbeing. All authors state more studies need to be done to address the above points.

Taking a multidisciplinary approach, Park and Shubair (2013) (Canada) call for the need to design effective interventions which examine physical, mental, psychosocial and environmental barriers. Additionally, Blinder et al (2012) (USA) suggest further studies are needed among breast cancer survivors of different ethnicities and socio-economic backgrounds. Although these studies go some

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[23] For example, Tiedtke (2012) is from the Department of Occupational, Environmental and Insurance Medicine, Katholieke University, Leuven, Belgium. See also Gudbergsson et al (2008), Clinical Cancer Research Department, and Occupational Health Centres, Norway and Finland.

way to inform the RTW process for women after breast cancer they are heavily reliant upon the clinician to act as gatekeeper for the provision of supportive care. Such schemes that involve closer liaison between health professionals and employers may not be feasible to implement due to economic downturn where cuts in health service budgets are being made or threats of privatization of the service will affect the health of all patients returning to work, not just women with breast cancer. As Maunsell et al (1999) point out, the same problems were highlighted two decades ago. The studies ignore factors already in place to protect workers such as disability and employment legislation and there is no discussion of how these laws are being interpreted and implemented into workplace practices. My research seeks to uncover this blind spot by interviewing HR and Equality and Diversity managers of employers to examine what policies and procedures are in place to support breast cancer patients RTW.

Any intervention steps as a means of support for cancer patients' RTW are seen as positive steps as the growing literature on this theme shows. However, I would argue that intervention cannot be implemented or practiced without understanding entirely how structural relations impact on women with breast cancer. Additionally, it would be difficult to measure on a case-by-case basis. Moreover, in the UK there are severe economic measures being imposed on hospital trusts to cut budgets, and prioritize needs whilst at the same time medical professionals are expected to be accountable and demonstrate best practice in their already stretched roles. Such economic restrictions would be likely to inhibit the development of such intervention schemes. Ideally, allocating nurses or other health professionals to follow patients step by step to recovery and back into work seems a logical support route. However, in practice it does not seem feasible when nurses are already under pressure to care for their patients in a safe and effective way.

3.2.3 Work practices

Johnsson et al (2010) interviewed sixteen women using the women's own narratives to expand the knowledge about rehabilitation after breast cancer. They looked at women's experiences of RTW after diagnosis, about how much contact they had with their workplace.. The study identified the health promoting impact of belonging to the labour market, which the women say "was a sign of returning to life" (Johnson et al 2010, p.139). Alongside the positive attitudes the researchers identified themes of continued struggle and discrimination in both their early returners and late returners. One respondent in the latter group who was sick listed for more than 12 months found that after rehabilitation, her employer asked her to agree to take redundancy. Another in this group experienced 'hostile acts' with their employers opposing their attempts to return to work (Johnson et al 2010, p.321). One respondent, because she could no longer do any heavy lifting, was told by her foreman "I think you should take an early retirement pension" (ibid). Within the early returners group respondents received valuable help from their colleagues but employers still expected the same job performance on their return. Although this study highlights some of the problems that women face on their return it would have been beneficial to know more about work demographics which Tamminga (2012) included in her breast cancer study. For example, she included employment characteristics in a socio-demographic table which I found useful and I adopted in my research to form a useful introduction to part one of my interview schedule (see Chapter 4). This flagged up possible issues around the type of work contract, number of years worked in present job role before diagnosis and whether this affected their decisions to return. In cases of work place discrimination, it also shines a light on issues around class, ethnicity and disability. It is beneficial to interview employers, whether matched to breast cancer respondents or not, to gauge a level of understanding about disability and working with cancer which in turn may highlight why discrimination occurs. Tiedtke et al (2010, p.682) stress that:

> initial reactions of the employer seem to be crucial, as these reactions represent the start of supporting the employee or discriminating against the employee.

Blinder et al (2011, p.768) reported a lack of flexibility or support for women after breast cancer and suggest this can lead to "early retirement or a complete change in career" which my research also shows. I discuss this further in chapter 5. In her US study, Blinder found "Black and Latina women have lower rates of return to work than non-Latina whites after breast cancer treatment". They found that women who stopped work during treatment were most likely not to return to work within a five-year period (Blinder et al, 2011, p.763). Latif et al (2015, p.2) also support these findings and add that breast cancer survival rates differ with ethnicity and are "greatly affected by cultural, economic, and social factors". Lindbohm et al (2014, p.634) also report:

> Older age, low education, low income, manual work, a high demand job, co-morbidities, undergoing chemotherapy as barriers for returning to work after breast cancer.

The level of support varies according to knowledge and understanding of different employers and despite there being support systems in place initially, for some women Shewbridge et al (2012, p.121) stress the importance that women place on work in their lives. Therefore, it is important that breast cancer returners have access to on-going emotional as well as physical support. They also need access to relevant information about their entitlements in terms of sickness absence under their work contracts and entitlements such as taking time off for hospital appointments. Employees need to know how their work ability will be assessed and appraised, all of which are part of the social support system in the workplace. But the authors found in their UK study that support "fell as treatment progressed" (Shewbridge et al, 2012, p.120). However, Nilsson et al (2013) found there were few studies on social support in relation to work ability and adjustments for breast cancer returners. In fact, they found "work life was the least experienced type of support: a third of the women had not received this" and also found, more worryingly, that support deteriorated over time (Nilsson et al, 2013, p. 2757). There are differences, it seems, throughout Europe and the rest of the world in terms of legislation which supports and protects employees RTW. For example, in Sweden according to Nilsson, employers have a "far-reaching legal responsibility to support their employees in their RTW efforts by

early contact regarding planning adjustment of the environment, tasks or task allocation" (ibid). However, both the above Swedish study and a UK study by Amir et al (2007) found that the longer the duration of sick leave, employees experienced more difficulties in returning to work. But where managers "made adjustments that directly accommodate work limitations reported by employees managing various chronic illnesses, [it] enabled them to not only manage their work, but maintain employment" according to Pryce et al (2006, p.6).

In order to examine what support is offered to women during or after treatment both in terms of physical and/or emotional wellbeing my research looks at whether an organization has policy procedures in place to assist a safe return and within this process, monitoring of skills/ability to work, which may equally involve managers and employees. I try to establish whether there are opportunities for workers to raise problems or address performance disputes. Johnsson et al (2010) do acknowledge that there is scarce information on women's RTW after breast cancer and state further research is needed to understand the negative consequences of long term sick leave and to identify the risks that women face in being marginalized from the labour market. My research aims to fill this gap.

3.3 Conclusion

The studies I have reviewed above share similar findings i.e. that there need to be better organizational structures in place to enable women to make a safe return to work. The studies highlight that there are many barriers for women returning which have been occurring over the past two decades as Maunsell et al (1999) point out. However, without examining relations of ruling within organizations these same problems will keep on occurring. This review has highlighted many useful studies which have informed my research. I have identified where there are gaps in their findings or if their research could be built on for example, Thomas-Maclean's (2005) work if placed in the whole context of women's RTW could usefully be extended. Most of the RTW breast cancer studies reviewed above have identified important barriers for women returning

but they have not explored the reasons why these keep occurring or developed strategies in their methodology to examine structural relations which may have shown the reasons for their findings.

Chapter 4 Methodology

4.1 Introduction

This chapter explores my research design and methodology and describes why its use is appropriate for this research project. I start by discussing methodological issues followed by a practical application of my research design and conclude by reflecting on specific challenges and limitations of the project.

The aim of this research is to conduct an exploratory study of the experiences of women returning to work after breast cancer. The sample is purposive and includes women who are employed full time, part-time, agency staff, self-employed, planning to return or have returned to work and women who have not returned to work for various reasons. It explores the time-frame from breast cancer diagnosis, their treatment and how they navigate their return or non-return to work. Many women are reported as wanting to get back to 'normal' after treatment and return to their jobs as soon as possible but there are those who struggle to return to their jobs for various reasons. The rationale for the study is to highlight the marginalized voices of women in this area. Each year over 55,000 women develop breast cancer (World Cancer Research Fund) [24] which results in more and more women being taken out of work. This may mean a temporary or permanent loss of employment and/or work ability.

4.2 Methodological issues

It is not possible to simply separate theory and method according to Fairclough:

> Settling on a methodology for a particular research project is not just a matter of selecting from an existing repertoire of methods. It is a theoretical process which constructs an object of research (a researchable object, a set of researchable questions) for the research

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[24] See http://www.wcrf-uk.org/uk/preventing-cancer/cancer-types/reducing-your-risk-breast-cancer

topic by bringing to bear on its relevant theoretical perspectives and frameworks (Fairclough,2010, p.225).

The methods which involve data collection and analysis arise out of "how the research object is constructed" (ibid). With this in mind, and having explored the theoretical process to construct a researchable object, the framework in which to place my research questions determined the type of methods that would be appropriate to capture how women with breast cancer navigated their return to work, how this disease shapes their sense of who they are in context to the social world around them, which allows or inhibits the ways in which they are able to navigate through their illness and back into the workplace.

Although it is not my intention here to discuss the merits of using either 'quantitative' or qualitative methods – for both have different pros and cons, it is important to note Letherby (2003, p.87) cites Oakley's (1998) who suggests that we avoid these terms as they "add neither insight nor credibility" as long as they are 'research specific'. It is more important to choose a method which is suitable to the research project i.e. the "topic and scale of the study" (ibid). As a lone researcher the parameters were limited to cost and geographical location therefore, some telephone interviews were carried out where face-to-face ones were impractical.

When designing this research project I adopted a case-centred approach treating each of my breast cancer respondents as individual case histories centred around the period from breast cancer diagnosis and treatment to return to work. At the same time, I wanted to compare the breadth of commentary across the different narratives and to continuously interact "between the theoretical issues being studied and the data being collected" (Yin, 2003, p.58). The collection of data from case histories has no formal plan. As a researcher I needed to be adaptable and flexible during my interviews and continually ask questions about why certain events happen and be prepared, as Yin suggests,

to accept that "your judgements may lead to the immediate need to search for additional evidence" (ibid). Care must be taken to avoid researcher bias about pre-conceived notions or having a good understanding of the issues before the research begins. In order to be open to contrary findings which starts at the data collection phase, close scrutiny of the data is necessary followed by discussions with research supervisors to avoid bias. This is not to say that researchers cannot place themselves as 'subject' by "placing one's own experience within the social context – [it] is also an antidote to feeling superior in research relationships and writings" (Letherby, 2003, p.9). Feminist researchers strive to ground the personal and be accountable to readers.

Choosing to use individual narrative cases of the women with breast cancer does not mean that it was not possible to generalize from the results as is the case normally with population based statistical samples. Reissman (2008, p. 13) states

> Making conceptual inferences about a social process…is an equally "valid" kind of inquiry with a long history in anthropology and sociology…major theories in the medical, natural, and psychological sciences were developed from close analysis of instances. Case-centred models of research can generate knowledge that, over time, becomes the basis for others' work…

This approach also allows me to situate my research in the methodological and conceptual gaps in this area.

Case-centred models are useful for generating new hypotheses which may be tested against other theories later, as many authors have done. According to Yin (2012, p.28) the role of theory helps you to focus on areas such as: deciding on a topic to explore; the nature of the cases under study; writing appropriately for descriptive case histories and stating theories of opposing positions in explanatory studies. If you wish to generalize from the findings of your case history it is helpful to refer to existing theory which may be relevant to your findings.

Using the personal narratives of women to understand breast cancer experience and RTW does not provide a complete perspective in itself but as Bourdieu (1999, p.618) would argue it can explore how the single account is related to certain actions and interactions which provide a more in-depth picture of why women take certain actions and make decisions about their life after breast cancer. Fairclough (2010, p. 176) makes this connection also and reminds us that "social science should include theories and analysis of both structure and action, and of their interconnection". Narrative can help to generate categories or patterns as the researcher is prompted to think beyond the surface of the text to push it into a 'broader commentary' (ibid) and because narrative travels across disciplines it offers a 'many layered expression of human thought and imagination although many will disagree on its 'origins and ways to conduct analyses (ibid). But importantly, collecting narrative is seen as participatory research which "enables the discovering of the social experiences of 'silenced women'…from the lived experience of the narrator…and offer a challenge to other 'partial' accounts" (Letherby 2003, p.89).

4.3 Feminist research, reflexivity and difference

What makes feminist research different from any other is the way in which it is framed and deployed. For many years feminist researchers debated over the notion of value free research practices as legitimacy was questioned over qualitative studies according to Maynard (1994, p.21) which involved some feminist researchers trying to "involve measurement and counting" (Letherby 2003, p.88). More importantly, Hesse-Biber, (2014, p.80) cites Letherby (2002; 2003) who argues that feminist research should "take account of, reflect on, and uphold human values.

As a feminist researcher trying to uncover "the subjugated knowledge of the diversity of women's realities that often lie hidden and unarticulated" (Hesse-Biber, 2014, p.184) it is important that the 'insider' and 'outsider' roles are

acknowledged. For example, I am an 'insider' in that like my respondents I have had breast cancer yet our experiences may differ and we may have inhabited different social fields which also makes me an 'outsider'. Letherby (2003, p.96) suggests that "many feminists…draw on their own autobiographies, when deciding what to study, when collecting the data and when analyzing the writing up". Putting the [I] back into Embod[i]ment and Exper[i]ence was not only a valuable resource in helping me decide on a research topic but it also enabled me to make sense of how other women with breast cancer navigated their way back into the workplace. Therefore, sharing personal experiences through interview seemed an appropriate method and lends itself well to exploring how illness and treatment regimes impact on a RTW.

Doing reflexivity was an important part of my teaching practice so it followed 'naturally' into my research. Not only is it necessary for teachers to reflect after a lesson but practicing 'reflection in action' allows both the teacher and interviewer to immediately react to a situation or moment creating an equal role for the learner/respondent where they can express their ideas and their voices can be heard. Some feminist researchers argue against "standardization of interviewer practices in qualitative research teams" (Hesse-Biber, 2014, p. 215). But reflective practice is an important tool which allows researchers to be aware of their own status and that of their respondents particularly as illness and work intersects race, class, ethnicity, sexuality and disability. There are many differences or 'distortions' as Bourdieu calls them, hidden in our research relationship that need to be understood. He states,

> …all kinds of distortions are embedded in the very structure of the research relationship. It is these distortions that have to be understood and mastered as part of a practice which can be reflective and methodological without being the application of a method or the implementation of a theory (Bourdieu, 1999, p.608).

He sees "reflexivity based on a craft, on a sociological 'feel' or 'eye' [which] allows one to perceive and monitor *on the spot* as the interview is actually taking place, the effects of the social structure within which it is occurring" (ibid). Two examples

illustrate this practice in my research. Firstly, when questioned by an interviewee whether I had had breast cancer and having acknowledged that I had, she began to open up and offer a more intimate shared knowledge. It was not my intention to share my experience unless I was asked although this did lead to me becoming a 'kindred spirit' and the respondent placing a great deal of trust in me. However, listening to the tape recording after the interview, I became aware that it was important to acknowledge my own preconceptions of my disease and also to recognize my responsibility as an academic researcher. Being a breast cancer patient and an 'insider' was useful too when I facilitated a focus group session for cancer patients who were at various stages of treatment – some terminal, some just beginning on their cancer journey and whilst respecting their differences I was seeking answers to my research questions. I didn't want to use this group formally so decided to put myself in the frame by announcing that I was a breast cancer patient and a researcher. This announcement enabled me to hold an inquiry question in my mind: How do I show empathy and be able to share the cancer experiences of this group of women and how will this be manifested? By holding this question close and working in the moment it allowed me to actively listen, show empathy, reflect in the moment and respond accordingly and this resulted in honest and open participation from the women. I was then able to move through my research questions in a relaxed way.

Some respondent's stories were so much a part of my knowledge and experience and the fact that I was not able to help or offer advice when they told their distressing stories was particularly difficult. I was not there as a counsellor but as a researcher. At times I felt I wanted to help my respondents but as Letherby reminds us, "such feelings may reflect our own needs – the need to feel better about the research and our involvement in it, or the need to feel useful" Letherby 2003, p. 127).

4.4 Research Design and methodology

4.4.1 Interviews

Three areas of data collection form a 'convergence of evidence' as suggested by Yin (2003, p. 98-100) for this research. My primary methods included two sets

of interviews: the first with women who have had breast cancer and the second with local employers' HR Directors. A case centred approach was adopted with my breast cancer respondents as I wanted to gather as much information about each of their work histories and their medical histories as possible (see 4.12). These medical and work histories were used to refer to during the interview and were also able to be grouped together to study patterns/themes in NVivo in preparation for my analysis. Focus group meetings were initially used prior to the start of my fieldwork in order to help plan my interview schedule and recruit respondents. Secondary data used to support this research was gathered from; analysis of social media blogs, policy documentation and similar studies. Yin cites Patton (1987) who suggests there are four types of triangulation in carrying out evaluation: 1) Data triangulation which collects information from multiple sources but studies the same phenomenon; 2) investigator triangulation where different evaluators are involved in analysis; 3) theory triangulation which involves applying different perspectives to the same data set and 4) methodological triangulation which uses a variety of methods. This research project uses all four but in 2) there is selected input from supervisors of the research team, for instance checking transcript coding for analysis in NVIVO. Triangulating evidence from different sources can 'shed light on a theme or perspective' which helps to provide validity to their findings' (Cresswell, 2013, p.251). Importantly, many feminist researchers draw on their own lived experiences when collecting and analyzing data. For example, Letherby cites Ribbens (1993, p.88) who argues:

> A critical and reflective form of autobiography has the sociological potential for considering the extent to which our subjectivity is not something that gets in the way of our social analysis but is itself social…I would suggest that the key point is that 'society' can be seen to be, not 'out there' but precisely located 'inside our heads', that is, in our socially located and structured understandings of 'my-self', 'my-life', 'me-as-a-person' and so forth. (Ribbens,1993 in Letherby, 2003, p.96).

Traditionally in interviews the researcher is seen to hold the balance of power particularly in structured interviews. She has the power and authority to set the agenda and ask the questions she wants, to prompt when she wants to know

more information or to 'call time' when she thinks she has enough data and considers that the interview should end. On the other hand, if the interview is too unstructured then there may be points of departure from the main questions especially when the interview is conducted in a conversational style. However, the overall advantage of carrying out in-depth semi-structured interviews was to explore new perspectives to gain an understanding and produce 'new knowledges' on the lives of women returning to work after breast cancer. New questions may be raised during the interviewing process and also for further research. It is difficult to continuously pay attention to what is being said during the interview whilst thinking ahead "to questions which might fall 'naturally' into the flow of conversation, all the while following a kind of theoretical line" (Bourdieu, 1999, p.610). Recapping and summarizing during the interview helps the researcher and maybe also the respondent, to monitor the flow in the telling of the story. It can also be a form of validation – checking the shared meanings used in the interaction. This was done at different stages in my interviews mainly to bring the respondent back to questions that needed more elaboration and to move the respondent forward.

4.5 Ethical considerations

Exploring women's breast cancer is a sensitive area of research. It is not just physically traumatic, it can be an emotionally distressing experience whereby patients remain vulnerable throughout their treatment, recovery and sometimes long after. At the start of the interview I outlined to the respondents that they may stop the interview at any time and could withdraw from the project if they wished. In the case of emotional breakdown, I was prepared to ask the respondent if she wanted to stop the interview. I also asked if the respondent had the name and number of a health professional they could contact for support in the event of emotional distress. This was a particularly important factor if my respondents were not part of a cancer support group or had no family or friends to support them. I had contact numbers of two main charities in the areas in which my respondents' lived in case they felt they needed support. My research is designed to respect the dignity and autonomy of my research participants at all times.

Adopting a model of continuous consent[25] rather than a once only agreement would give the respondent an opportunity to opt out of the inquiry at any time if the inquiry caused any emotional stress during in-depth interviewing. (Richards & Schwartz, 2002, Allmark et al, [26] 2009) Feminist researchers Cook & Fonow (2007)[27] adopt certain principles and stress the need for continuous reflexivity. I practiced reflection in action during the interview process to limit stress on my respondents as well as reflecting during the analysis of data. Following the ethical guidelines of the British Medical Association, the British Sociological Association, and the MRC, we need to critically reflect on the social context in which the research takes place. This was crucial when I interviewed women with breast cancer in their own homes. Additionally, feminist researchers Stacey (1988) and Oakley (1981) highlight trust as an integral part of the research process. I worked hard to gain the trust of my respondents and to respect their wellbeing and anonymity at all times.

There are few guidelines offered regarding the safety of the researcher. To ensure my own safety I ensured that I had notified someone of my interview appointment and provided my supervisors with informant's names, dates and times of interview and location. I had arranged to email/text my supervisors on completion of the interview to inform them if there were any adverse incidents or harm caused to either my respondent or myself. No incidents occurred.

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[25] Richards, H.M. & Schwartz, J. (2002) *Ethics of Qualitative Research: Are there special issues for health services research*? Family Practice, vol 1: 19.2

[26] Allmark, P (2009) *Ethical Issues in the use of In-depth Interviews: Literature Review and Discussion*, Research Ethics

[27] These principles of feminist knowledge include (1) continuous reflexivity on significant gender relations as part of the social, including the conduct of research (2) centrality of consciousness-raising as a specific methodological tool and as a "way of seeing (3) challenging the norm of "objectivity" that assumes a dichotomy between the subject and object

I received full ethical approval from London Metropolitan University. It was not necessary to get MREC approval as I was not using NHS facilities or interviewing NHS staff. Before interviews were carried out I sought permission in writing from my prospective respondents. Each received an information sheet about the project and once permission was obtained, approval forms were completed at the beginning of the interview. I assured my respondents at the start of the interview that confidentiality of information supplied by them would be kept secure by password access only to my personal computer files. Data would be erased after completion of the project. If direct quotes are used from the interviews in future research papers, I guaranteed the anonymity of my respondents or seek their permission to be included in any future academic papers.

4.6 Interview Schedule for Breast Cancer Respondents

There are a series of formats that can be adopted in the interviewing process which can be likened to running along a continuum which goes from 'informal' to 'formal'. For example, my interview schedule contains topic questions which guide the respondent through the interview. They are often adapted to suit the respondents' work situation i.e. whether or not they have returned to work. Both ends of the continuum can be seen operating in the schedule.

I wanted to vary the structure of the interview schedule to include both formal and informal parts. (see appendix A). In the introduction an informal outline of the interview process and health and safety check started the interview. This was followed by Part one which was a formal questionnaire type inquiry to briefly record 'Disease' and 'Work related' characteristics which were used as attributes to examine patterns and cross-based analysis in NVivo, for example, all women who have had chemotherapy and have returned to work compared with those who did not return. Part Two uses an informal structure in order to gain as much in-depth information about the three main topic question headings as possible –

see appendix 1.   The topic headings and prompt questions formed a guide of the subject area to be covered.   The respondents were free to move between topic questions. Each interview lasted approximately one hour.

4.6.1 Interview Schedule for HR Directors

In these interviews I was collecting the official narratives of organizations and the perceptions of senior staff which were used to triangulate with other data. There was an ethical consideration here as the informants did not wish to be identified. This meant that I was not undertaking a traditional case study based on the organization but was collecting narratives from HR from a range of sources to compare this with the narratives of women with breast cancer. This showed how official policy and other discourses played out in organizations. In order to explore relations of ruling a separate interview schedule was used to elicit information from organizations about whether their equality and diversity policies facilitated a safe return for breast cancer patients within these organizations. The data from these interviews with HR were not matched with my breast cancer respondents but provided additional key information about policies and work practices. This interview schedule was more structured than that used for the breast cancer respondents (see appendix B) for interview schedule. Organizations preferred telephone interviews because of their busy schedules and these lasted between 30-45 minutes.

4.7 Sampling frame

4.7.1 The recruitment of breast cancer respondents

Respondents were drawn from a wide variety of occupations and backgrounds and my geographical area included: Devon, Cornwall, Somerset, Dorset, Gloucester and Hampshire. As a self-funded lone researcher it seemed practical to conduct telephone interviews with those respondents who lived more than 20

miles away from my home in Devon – some respondents preferred to speak on the telephone rather than face-to-face. This saved time and expense in travelling to the respondents' home. Telephone interviews create anonymity both for researcher and respondent, which can create a more relaxed atmosphere for some people. However, this created limitations in terms of noting body language, particularly making eye contact when the respondent was speaking. I was unable to use a silent probe for example to gesture with a nod to let my respondent know I was attentive. The alternative was to use 'uh-huh' or 'I understand' probes but using these create difficulties during transcription. Also, some words were not audible and had to be played back several times.

Face-to-face contact involved a more participatory feel compared to telephone interviews putting both researcher and respondent on a more equal footing - the respondent welcomed me into her home. Peer-to-peer interviewing according to Hesse-Biber (2014, p.217) enables "individuals to talk about highly sensitive topics especially to someone who might have experienced a similar sensitive issue" which was the case with one respondent who asked if I had experience of breast cancer. This seemed to create a more balanced relationship as soon as I confirmed my position.

Details of each respondent's 'Work-related' and 'Disease-related' characteristics were drawn together in a grid. This formed Part One of the interview process and could be used to check information during the interview and also to analyze data in NVivo.

Two pathways of recruitment were used. Firstly, a flyer was devised and distributed at TUC SW and Union Learn Conferences followed by mail shots to all union reps in the South West and relevant cancer charities. Respondents were asked to complete and sign a consent form prior to the interview. Despite this mailshot to each union, the response was disappointingly low – three respondents emailed me wanting to take part. Secondly, a local health and

wellbeing centre running a Cancer Café was used to facilitate sessions and recruit respondents. Here, Macmillan training was provided to all facilitators of the Cancer Café which enhanced my skills needed in the interviewing process. Although no respondents were recruited through the café, I was made aware of two focus groups in my vicinity which I attended and recruited several respondents through these.

The sample group was small involving a total of 16 breast cancer respondents who were invited by email to take part in the interviewing process. I selected five major employers in the South West, not matched to my breast cancer respondents, but to act as additional key informants. Guided by time and resources and following Denzin (1994, p.202) I chose purposive over random sampling, as it allowed me to "seek out groups, settings and individuals where…the processes being studied are most likely to occur". Choosing a small sample group was appropriate to explore how individual women make sense of their breast cancer experience and return to the workplace and exploring their organizational practices gave a useful insight into how employers viewed breast cancer as a disability. Carrying out interviews with a small sample of women with breast cancer allowed me to explore attitudes towards body image and work ability. The sample was purposive, targeting women who have had breast cancer in the past five years and who were returning or not returning to work. Small sample sizes can be justified on the strengths of the procedures - how they are described, whether their procedures are fully explained so that other researchers can judge the research in the appropriate context.

It is necessary for the researcher to say "how the sample affected the findings, the strengths and weaknesses of the sampling procedure, and any other design decisions that are relevant for interpreting and understanding the reported results" (Patton, 2002 cited in Hesse-Biber, 2014, p. 192).

A small sample size does not always affect the research findings. For example, Tamminga (2012) conducted interviews with just 12 women as part of her study. What I consider a weakness however, is not having a wider range of types of employment of prospective respondents. In section 4.10 below I explain why I did not have a platform to advertise for recruitment through research partnership as I had originally hoped which limited the methods used. For example, I had originally intended to administer a questionnaire prior to interviews using the resources of a charity website. But as Letherby (2003) states:

> Not having much money or much opportunity for large-scale work is not always a disadvantage, as the researcher may be able to be more flexible and responsive to changes…" (Letherby, 2003, p.101).

I did have to be flexible and made changes to incorporate a questionnaire into part one of my interview schedule and adapted my method as Letherby suggests.

4.7.2. The recruitment of HR Directors

Recruitment of HR Directors proved difficult for two reasons. Firstly, there was some initial reluctance to participate in interviews. Secondly, there seemed to be some confusion over who would be best placed to answer my questions. Progress was slow with many back and forth emails trying to persuade each organization of the importance of the project. The first interview was secured through an introduction made by Prof. Sonia McKay at London Met and a second by recommendation from a CEO. It took a year to secure all five interviews. Due to these difficulties I concluded that interviews with the two groups: HR Directors of five organizations and the sixteen breast cancer respondents would not be matched.

4.8 Breast Cancer Support Groups

Originally, I had wanted to carry out a questionnaire prior to interview. I approached a breast cancer charity to partner my research and proposed the idea of using their website to recruit respondents. Unfortunately, my application was turned down because the research topic was not deemed useful to their supporter groups. They advised me to contact a local support group which I did. After networking at a health and wellbeing conference, I was invited to present my research to two cancer support groups. I used these groups as a focus to explore research topics and to recruit respondents for interview. These group sessions provided rich sources of information and ideas for formulating questions for interview although these discussions were not recorded or used as part of my research data. However, they also provided an opportunity to recruit breast cancer respondents through snowballing. They offered a safe environment for the discussion of sensitive issues surrounding breast cancer experiences. Group members already knew each other and there was an established trust amongst its members. Recruitment is made easier as the researcher builds up a relationship with group members who might be possible respondents. This was the case with one support group where I recruited respondents after gaining the trust of its members, mainly because the members knew that I was a breast cancer patient some years ago. I was able to take part as an insider, sharing ideas and experiences.

The second support group where I was invited to talk about my research, shared a different dynamic from the first group. I recruited a respondent with sensitivity to electro-magnetism and was interested in how she discussed this with other members of the group who were open to exploring wider environmental health issues which they were not aware of and which were not commonly known (see chapter 6).

4.9 Data Triangulation of the use of additional Key informants

I decided to combine different findings from other sources to complement my primary data which Quirk, cited in Silverman (2013, p.287) proposes as data triangulation. Additional information from interviews with HR in five organizations provided a picture of how large companies react to and deal with breast cancer as a disability both in terms of policy and in practice. Silverman also advises researchers not to "invent the wheel; find what has worked for others and follow them. (Silverman (2013, p.40). This was a practice I carried out as part of my literature review in chapters 1, 2 and 3. but researching what others have done before is a never-ending job and constantly needs updating. One way of keeping up-to-date with health issues particularly related to breast cancer and RTW is through journal articles of which there are many that have come to light in my results chapters 5, 6 and 7. These up-dates occurred right up to the final submission of the project. In order to explore a range of narratives articulated through social media I visited internet based social media resources (listed below). Silverman (2013, p.55) cites Kozinets (2010) who describes this as netnography which involves:

> The analysis of existing online community conversations and other internet discourse combines options that are both naturalistic and unobtrusive – a powerful combination that sets netnography apart from focus groups, depth interview, survey, experiments and on-person ethnographies (Kozinets, 2010 in Silverman 2013, p.56).

4.9.1 On-line blogs

For this research on-line blogs for cancer patients were accessed over a two-year period. Two main sites were monitored regularly for comments on RTW after breast cancer and workplace experiences. These were Macmillan Cancer Support and Breast Cancer Care. I wanted to find out about the experiences of cancer patients, their treatment and how they coped with a return to work. These mainstream charities are well known to the public and represented large memberships. Both these sites are open to the public and although I registered as a user with Macmillan's site I did not enter into conversation with its users. I made fortnightly visits to the Breast Cancer Care site but did not register with this site as it was open access. I used both these sites as an observer to view the

notice board for topical information. I realised that the diversity of media inquiry is problematic for sociological inquiry because of its journalistic style of reporting. However, on-line blogs are being used more and more offering a platform for users to share opinions on a range of topics – health websites and blogs are no exception in this ever increasing market.

The use of social media offers a central focus on women with breast cancer through charity blogs but it can also be used to reinforce mainstream medical opinion. I signed up to Macmillan's cancer blog as it offers a rich source of texts mainly from women who have gone through cancer or are just starting their cancer journey. Other personal blogs such as: https://stelladuffy.wordpress.com/my-books/ provide an insight into the language of breast cancer. Blogs provide ideas about how gender is constructed in mainstream society and how dominant ideologies contribute to our understanding of the operations of power. Feminists study the media as "it seeks and brings to the foreground the expression of muted voices and critiques the patterned discourses that support and reflect dominant ideologies of gender" (Hesse-Biber, 2014, p.267). New forms of multi-media can be used by researchers to gauge opinion, investigate social change and chart how new "meanings break out of the traditional moulds and advocate for the promotion of gender equality" (ibid). This raises more ethical considerations for feminists and social justice researchers. Hesse-Biber 2014, p. 319) cite Stanley and Wise (1983) who state there is need to "redefine the process as 'research with' or 'research for' rather than 'research on" in order to value research participants. The media represents discourses in a particular style sometimes only reporting "problems that emphasize the extraordinary."

Deconstructing texts to examine power relations involves multiple readings of nuanced relationships. This also raises issues around moderation and power. We are surrounded by media texts and images in our everyday life which appear 'normal' and only through careful examination can we uncover the relations of ruling that propose certain discourses and discard others. For example, blogs

that are set up by cancer charities can be seen to include women's voices as they raise questions about their various cancer experiences but at the same time reduce or limit information of a certain type. The discussions of the two well-known cancer charity blogs I analyzed, rarely feature information that challenges mainstream thinking i.e. the environmental causes of cancer that are discussed on lesser known sites. However more on-line space is used by individual bloggers to challenge and develop women's issues that are overlooked by mainstream organizations. For example, Diana Ward, principal writer on www.frompinktoprevention challenges the dominance of the cancer industry offering a global perspective. Others offer discussion boards and mailing lists for users to participate and take action. But there are few sites which might challenge the levels of autonomy in blogs and other social media generally.

Orgad's (2005) study *Storytelling online: talking breast cancer on the internet* uses virtual methodologies to explore on-line texts from email discussion boards, blog posts and social networking sites. This raises important questions such as, do these texts offer discussion on "important points pertaining to gender in regard to race, class or sexuality, thus inviting further inquiry?" (Orgad, 2005, p. 282). To this I also add disability.   From these texts workable themes form patterns both within a text and across multiple texts and their interconnectedness. A theme may be connected to "cultural ideas outside texts. A text never emerges from a vacuum. Instead, it becomes the product of multiple contexts…these contexts influence not only a text's production and the ideas it represents but also its uses and receptions" (Orgad, 2005, p. 284). For example, in Chapter 7.3.6 the Macmillan bloggers are arguing at times in multiple contexts: breast cancer diagnosis, employment conditions and seeking advice from Macmillan. Although monitoring of these blogs played only a small part in my research, they helped to shine a light on employers' attitudes to breast cancer patients returning to work.

4.10 Piloting the interviews

Once ethics approval was granted by the University and the basic design of the research was completed and checked with supervisors, a research timetable was

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constructed outlining fieldwork activities, written work and the date of final thesis submission, then the pilot interviews began. Some changes were made to the interview schedule after the pilots.

Pilot interviews were conducted with two respondents and the interview schedule was modified for the interviews that followed. The schedule now consisted of an introduction and two parts: the introduction covered some ethical issues: assurance was announced (and recorded) to all respondents that the data would be anonymized and kept confidential at all times; and a reassurance was given that their health and safety would be secured - that they could decide to stop the interview at any time and they had the right to withdraw from the project at any stage of the process.

In the first stages of designing the interview schedule, questions about employment and disease characteristics were incorporated in the story. This made it difficult for me to follow the information in line with questioning during the story and by referring back to these characteristics it interrupted the flow of the conversation. It made sense, therefore to separate this information into two parts. Making Part One into separate questionnaire style grids of information (see below) allowed me to view characteristics at a glance and be able to quickly refer to them during conversation if needed.

Work-related characteristics

Name	Ethnicity	Work Status before Diagnosis	Contract Full, P/T other	Years worked	Hours Worked	Shift Work	Work Status at Int.	contract	End of Treatment

Disease-related characteristics

Name	Age at Interview	Age at Diagnosis	Type of Breast Cancer	Treatment surgery	Hormone Therapy	Chemo-therapy	Radio-therapy	Duration Of Treatment	End of Treatment

After reflecting on the practical difficulties of having no platform to administer this questionnaire it became obvious that a questionnaire, on a much smaller scale, could be incorporated into the interview as Tamminga (2012) had done in her study of breast cancer survivors and RTW. Part two then allowed the women to tell their stories starting from the breast cancer diagnosis and following through to their return to work. Both parts were audio taped. Locating the information grids in part one secured accurate information about employment conditions, time sick-listed, type of cancer and treatment and return to work adjustments etc., which could be referred to quickly during the interview when needed and for data analysis. Part two now led into a more informal conversational style interview where the respondents were able to relax and tell their stories.

4.11 Transcription

All interviews were audio recorded and were carried out either face to face or by telephone depending on geographical location and/or respondent's preferences. Two respondents preferred to remain totally anonymous and requested telephone interviews. One respondent said she felt more relaxed this way. Field notes were made after each interview had taken place. These reflections were useful both in terms of monitoring how I reacted to the interview. This presented an opportunity to examine personal bias and pre-conceived ideas, my own and those of my respondents, but also to ask questions about whether familiar themes were arising.

4.11.1. Thematic Analysis

The aim of this research project was to allow women's voices to be heard about their experiences of returning to work after breast cancer. The choice of thematic analysis was threefold. Firstly, this allowed me to bring to the fore women's individual experiences - what was being spoken about. Secondly, it detected similar themes that appeared across multiple texts in my data and lastly, themes emerging from existing scholarship could inform the project. There is no straight line in developing themes - they can change through your research inquiry. The research can see more themes appearing as the texts become more detailed.

They also connect to the wider social agendas, for example cultural ideas outside the texts. "A text never emerges in a vacuum" according to Hesse-Biber (2014, p.284). Making sense of the data means following a cyclical path, visiting texts many times in a back and forth way.

In the management of data, such a cyclical path is offered by Cresswell (2013, p.182), a strategy which I adopted in the collection, data analysis and writing up my research. The procedure operates in spiral loops ensuring the researcher moves round in analytic circles between what appears in the text, i.e. what is said and chosen for analysis, and also what exists in the existing scholarship. It is useful in that it engages the researcher in the "process of moving in analytic circles rather than using a fixed linear approach" (ibid).

The recordings were transcribed verbatim and the transcripts were read through several times and roughly colour-coded by hand, this means taking a segment of text and giving it a category or theme. Initially this involved either literal or focused coding. Eventually, coding was modified which moved it to the next stage ready for analysis in NVivo. This then takes the data from a literal plane to a more abstract form. The transcripts not only included text but also non-verbal communications such as tearfulness and laughter which were included in amongst the verbal comments. Pauses and silences were also noted.

The transcripts were uploaded to NVivo ready for coding and computer-aided data analysis. This allows the researcher to search the whole data set rather than selecting anecdotes used to support an argument avoiding bias that could enter the analysis. NVivo can be used to make comparisons across large amounts of data which can be categorized into coded segments quickly and it can also note the number of times that things occur. For example, it showed the number of women who had gone through chemotherapy or who were treated fairly by their employers. It allows the researcher more time to think about the data and its meaning. However, adequate time is required to familiarize yourself with the

software and you still have to spend time thinking through your codes, read the material and apply the coding. Once this is done the analysis is faster than by hand and the researcher is able to demonstrate that "conclusions are based on rigorous analysis" (Silverman, 2013, p.270). Looking for themes and patterns demands detailed reading and record keeping. Whether the researcher uses pen and paper or computer software for analysis, the process involves reviewing the data multiple times, questioning each time asking, what does this mean? And only when there are no new questions that raise new insights then this results in saturation. Only then can the results be written up.   The next chapters report on these findings.

Reading and memoing was involved in the first loop in the spiral of my research, in order to select how my data was organized.   The transcribed data was uploaded into computer files ready for classifying and coding. Before coding took place, interview transcripts were read several times along with field notes so that I became familiar with content and to get a sense of the data as a whole. Notes were made in the margins of the texts where I needed to follow up certain theoretical points. For example, I wrote a memo to myself constructing a field map based on Bourdieu's (1977, p.168 & 184) concept of field and how some players have the power to dominate others in a particular field. In my research, this involved all players involved in the field of health and work. At this stage I reflected on my research questions to check on how the evidence related to the three main topics, knowledge construction, return to work and work practices. Some loose coding began at this stage as key concepts were identified.

Interpreting and coding data thematically is an approach that has been used to "uncover and categorize thematically patients' experiences of illness" (Reissman, 2008, p.53). Riessman (2008, p.55) cites the work of Williams (1984) who uses thematic analysis to research illness. Firstly, Williams works with each individual interview at one time "isolating and ordering relevant episodes" (Riessman 2008, p.57).   At the end of the process he "zooms in, identifying the underlying assumptions in each account and naming (coding) them" (ibid). He then selects

particular cases to illustrate general patterns, which I did in my research. But as Riessman warns, we must not assume that "everyone in a thematic cluster means the same thing by what they say (or write) obscuring particularities of meaning in-context" (Riessman, 2008, p.76).

I started Coding mainly from the respondents' own words, for example, 'hair loss' and 'body image' was a recurrent theme that began to emerge from the texts. This in turn prompted another spiral as I looked to existing scholarship to see what others had already found. I made notes here about what was unexpected and what was missing from existing scholarship - this related mainly to the lack of any theoretical framework in their studies which lacked social mooring.

Coding in NVivo allowed the large volume of work transcribed in my transcripts to be uploaded and become part of a computer-aided data analysis. This led to searching the whole data set rather than selecting anecdotes used to support an argument. However, adequate time is required to familiarize oneself with the software and considerable time is needed to think through appropriate codes, reading the material and applying the coding. Once this is done the analysis is faster than by hand and the researcher can demonstrate that "conclusions are based on rigorous analysis" (Silverman, 2013, p.270).

Moving out of NVivo to interpreting the data is another circle in the data analysis spiral. Cresswell (2013, p187) states that this "involves abstracting out beyond the codes and themes to the larger meaning of the data". Interpretation in relation to this project sits firstly within the framework of social sciences focusing on the research questions and key theories, namely, the relations of ruling. Secondly, the interpretation of existing scholarship and related documents and reports is also factored into the analysis. The results (Chapters 5,6 and 7) represent the final phase of the spiral. Examining what I found in my research data and comparing this to existing scholarship was useful as it exposed false distinctions

such as mind/body dualisms, unexpected or surprising events and raised questions for further research.

4.12 Challenges of the project

Initially, recruitment of respondents was the biggest challenge to the project. I had originally focused my recruitment drive in three South West counties of Devon, Somerset and Cornwall but eventually had to extend this to Dorset, Hampshire and Gloucester. I wanted to involve more trade union members in the sample and despite using South West TUC conferences to distribute my information flyer and a mailshot to all trade unions the response was disappointingly minimal (only three Trade Union members replied). Originally, I had planned to administer a questionnaire and invite some of the respondents to participate in an interview. I contacted two major cancer charities in the hope of using their resources (respondents and website) to recruit breast cancer respondents. After submitting a research application to a major breast cancer charity I was told that the research would not benefit their members. Both charities advised me to consult locally which I did and found local focus groups. Eventually, through snow-balling and with the help of a trade union colleague from my department I began to slowly meet my targeted sample of 16 breast cancer respondents. One referral came through a breast care nurse from my local hospital. I had met her as a patient myself some years before and she agreed to put up a flyer in the breast cancer clinic.

Recruiting organizations for interview was extremely slow. It was necessary to make adjustments, acknowledging this would have limitations - my breast cancer respondents would not be matched with the five organizations as this would have created a further delay in my research timetable. At first there was some reluctance from organizations to participate in the project. It took several emails stretching over a year before each organization found the appropriate person who was willing to be interviewed. I had to extend my timetable to accommodate these right up to the last moment possible in order to secure these interviews.

Reflections from fieldwork notes reminded me of the difficulties in listening to women's stories, their struggles to fight prejudice whilst coping with the effects of treatment on their RTW. I felt compelled to make things 'right' feeling a strong sense of injustice at the way that some employers were treating breast cancer returners (see Rachel's case study in chapter 5). I was also aware that research does not result in actions to be taken – there may not be a resolution to a conflicting situation or clear recommendations to carry forward for future research. The management of emotions for any researcher is complex. In any given situation of feminist politics, it seems to me that we should challenge injustice but for now these emotions remain as reflections in my research journal along with other thoughts to be acted on later.

I tried to keep the research relationship with the breast cancer respondent's fluid in a way that the interviews were jointly managed. I respected respondents' moods by not pushing too hard if they did not feel comfortable about going in a certain direction. I did find that the conversation returned many times to the diagnosis and treatment which still remained prominent in their minds. However, I found my role as researcher was much less emotionally involved with the HR Directors who were also women. There existed a professional distance, which at times seemed almost like we were running through a business agenda. These formal interviews had an agreed time limit due to their busy schedules. The response to my questions were measured, sometimes guarded and felt rehearsed compared to the heart-felt replies from my breast cancer respondents. It was easier to call time with the HR Directors because of the formal nature of the interviews compared to the breast cancer respondents who talked freely in a relaxed conversational way. My field work notes recorded a certain reluctance on the part of the HR Directors to be interviewed but this may have been due to the fact that they were not used to being interviewed about such sensitive areas. However, they did find it easier to talk about policies laid down and sickness absence in a statistical way.

In conclusion, this chapter has explored my selected research design and methodology and describes why its use is appropriate for this research project. I have outlined the practical application of my chosen research design and discussed some of the key methodological issues. I have reflected on specific challenges and limitations of the project, recruitment being the main challenge initially. Working as a lone researcher without the backing of organizations such as cancer charities or trade unions has meant that it has taken longer than expected to recruit which resulted in amendments to my methodology and research timetable. Throughout this fieldwork phase I have tried to practice critical thinking along every step of the research process focusing on "what we do and the relationship between this and what we get" which Letherby (2003, p.160) suggests is an essential part of feminists' work although not exclusive to it.

Chapter 5

Conflicting Narratives of Breast Cancer

5.1 Introduction

Each of my three research questions represent a framework under which my data will be analyzed and discussed and will form three separate chapters. Theoretical perspectives and empirical data from other studies will be woven through my research data as the discussion takes place. The coding responses of all interviews analyzed in NVivo have provided elements which will help in answering my research questions.

This chapter asks: How do women who have had breast cancer construct personal narratives of the disease and how do these contrast with dominant medical ideologies and models? I will start from the women's experiences of diagnosis, their access to medical information and how they make sense of this in contrast to their own lay knowledge and experiences. I also explore how patients experience loss of identity through surgical changes to their bodies which manifest in various ways - both physically and mentally after treatments. Breast cancer is not just an experience which can be viewed in isolation but one that "takes shape and acquires meaning through such aspects as historical and cultural frameworks…in which breast cancer imagery has been constructed" (Crompvoets, 2006, p.27).

Each day new cases of breast cancer disrupt the lives of women and their families. Incidents are rising by approximately one percent each year which means that more and more women suffer distress on diagnosis and disruption to their working lives due to treatment and its after-effects. It is the "leading cause of cancer deaths among women in most developed countries" (Mokbel, 2002, p.972) which for some women causes shock, depression and loss of identity as well as fear that the disease may return. Women throughout Western Europe

and North America have a 10 % chance in their lifetime of developing breast cancer despite it being the subject of much research and improved technology with continued calls for effective prevention strategies. Researchers of health and primary care suggest that general medical practice involve partnerships between researchers and respondents thus involving a wider range of co-producers of health (McKinley, et al. 2002). If we are to encourage widening participation to this extent and enter into proper and respectful debates between all concerned as McKinley suggests, then women's personal narratives of breast cancer experience should take centre stage to enable us to examine their questions, fears, their ideas and their health needs. In chapter two I discussed how feminist theories of embodiment have helped us understand how dominant medical models constrain, medicalize, normalize/feminize women's bodies which are measured against artificially constructed binary pairs of able/disabled, coping/not coping, wellness/sickness. The majority of research in this area argues that research confined by these medical models ignores important social concerns of patients, their questions and beliefs, some of which, I outline below. There are, however, some examples of how medical professionals are beginning to take a more holistic view of women's health which I discuss here.

The participants in this study were sixteen women who were diagnosed with breast cancer, four of whom had experienced either the return of another primary breast cancer or metastatic breast cancer. One woman had experienced four occurrences, the first at age fifty one, the last at seventy four. The women's ages at diagnosis ranged from twenty nine to seventy four. The youngest participant aged 29 had opted for lumpectomy only and no further treatment. Nine women had mastectomies and had radio-therapy, nine had chemo-therapy, and five women had combined radio-therapy and chemo-therapy. Three women had reconstructive surgery. Of this group, one woman had to have her implant removed due to another primary tumour in the reconstructed breast and a second had a reconstruction at the time of breast removal. One woman had ovaries removed and a breast reconstruction.

5.2 Receiving a breast cancer diagnosis

Generally, it is the surgeon who presents a breast cancer diagnosis to a patient. Working on certain principles which are encouraged by the medical model, the physical body, when found to be diseased, is separated from the mental body. So the process of dualisms begins with the diagnosis - the mind and body are separated. The physical body is something that must be cured like the dysfunctional part of a machine to be fixed. Hayes and Prior (2003) highlight that there are problems in using different theoretical models chosen by researchers that become separated into biomedical, psychosocial, epidemiological and socio-political domains. Gendered health is a product of all four domains and although these models may seek to explain inequalities, "they need to be placed in the wider socio-political context of modern society" (Hayes and Prior, 2003, p.4-7). The authors state that the two competing models to measure health, the social and the medical model are used by many as an ideal standard although the first, they say, is almost impossible to measure. For example, the social model is described as a state of complete physical, mental and social well-being whereas the medical model is seen as an absence of disease symptoms.

At first, the social model definition appears 'complete' but how are its constituent parts broken down to be measured? There are difficulties in using both models. Examining gender inequalities in health may converge with race and disability. If one inequality is prioritized over the others it then separates these other issues of women's health which become marginalized or ignored. This results in a diagnosis presented via a reductionist medical model according to Atkinson (1988) that "privileges such explanations at the expense of social, cultural and biographical…the individual patient is a more or less passive site of disease manifestation" (Aitkinson, 1988 cited in Nettleton, 2006, p.2).

A central theme that emerged from my research data when the women were given a breast cancer diagnosis was their emotional response to this devastating

news. Some women recalled this moment as being in a state of shock, in denial, terrified, numb or did not really take in what the surgeon was saying. Judith, a college lecturer, diagnosed at fifty three, expressed:

> I think cancer is something that just happens…it's like being knocked down by a car (Judith).

Elizabeth, a GP, diagnosed at fifty, reported:

> I had just had a 50th birthday and I was thinking, I will be getting a mammogram soon…then I found a lump. I was aware of surgical procedures and types of reconstruction and different types of cancers but just the impact it has on people's lives hadn't really hit home until I had it myself. My first thoughts were, I don't do this, I don't actually get ill, this isn't on my agenda…I haven't got time for this (Elizabeth).

Fear and anger were emotions that Louisa, a telecommunications manager, diagnosed at thirty nine remembered:

> I was so angry, it was ridiculous. I had no idea where that anger came from. I wanted to walk out like everything was normal although nothing was normal. I remember thinking vividly that the world had completely stopped for me and yet the rest of it was whizzing on by on its axis as if everything was normal. Basically, I didn't deal with it very well. I was terrified. I had to ring back to find out what happens next. I hadn't taken in anything that they had said which is why they say you should take somebody with you (Louisa).

Pauline, a Medicines Management Technician, diagnosed at fifty three, felt numb on hearing the diagnosis:

> I think I just shut down to be honest…I was told in a really strange way…it was a normal three-year mammogram when they discovered it and I knew there was something…and they said what is the best phone number to get hold of you? And I was thinking, this is a bit dodgy! I needed another mammogram and had to have biopsies done and still wasn't told anything at this point. The nurse specialist put a box of tissues in front of me…she was so 'round about' and she said 'well this confirms…do you want to see the x-rays…' at that point I just turned off. A couple of days later [the consultant] he went through it and said, 'You fit the criteria for having a mastectomy and a reconstruction and it's got to be done in 28 days'. All this was   going over the top of

my head…even now 5 years later things still come back what happened while I was in the hospital" (Pauline).

For Joy, a consultant, diagnosed at fifty seven, the news simply did not register:

> They probably gave me everything I needed to know about it at the time but you know…you just let it go over your head (Joy).

Wendell (1999) suggests, there is a need to accept that some kind of transcendence of the body has to take place due to illness. This is important if women are to negotiate the biomedical world of breast cancer and how knowledge construction shapes their thinking of health and illness.

An example of how knowledge construction shapes thinking is shown in the following statement of how Judith rationalized it:

> That's how statistics work – somebody has to get it and it was me. One of the funny things, annoying things about having cancer is everyone telling you why you have had cancer. I am a fairly healthy person, I don't drink, I don't smoke, I'm not overweight. I've no idea why I got cancer but somebody has to get it, it is one in nine. I don't think I need a reason (Judith).

Pat, self-employed, diagnosed at sixty eight, went along with what her surgeon recommended:

> The surgeon was quite adamant. She was lovely. I felt perfectly happy with her. I felt quite pleased that I was going to have a mastectomy strangely enough because I had heard so much and read things about people that had had lumpectomies and then it comes back and I thought well at least it will get rid of that (Pat).

Some patients like Evelyn, unemployed, diagnosed at fifty seven, demonstrate how women feel when they are made to think that they are wasting a doctor's time:

The day I went for tests, you meet up with a doctor first…you lie down so she can feel the breast and I knew what she was going to say, 'where did you say this lump was? She was quite stand-offish to begin with. After the biopsy she bent over backwards almost – 'well aren't you a clever girl' those were her exact words. There was something there after all and her attitude changed because obviously I wasn't wasting her time (Evelyn).

For Shirley, a cleaner, diagnosed at forty two, it was important that she tried to remain positive in front of her children:

I found a lump but didn't think anything of it to start with but then it bugs me and because of my age (42) I thought I would go and get it checked out. I said to my husband that I had found a lump and he said it's probably a little cyst. Though I always try to be a positive person and know my own body I thought, it's going to be breast cancer. When they showed me the scan it was about three and a half centimetres, about the size of a golf ball. My daughter was just starting her GCSE's and I said to her, 'you know, I'm not going to die…that's not what they have told me and that's not how I feel'. I said 'it is treatable – I will be having surgery, chemotherapy and radiotherapy but you concentrate on your exams and I will concentrate on me'. And she did fantastic…I tried not to show it but it did get me down at times. It is not fair on them [children] any upset they have so I waited till either they were at school or in bed…you know (Shirley).

Two problems merged into one as Ruth, self-employed, diagnosed at fifty, suffered sensitivity to electromagnetism without having had an official medical diagnosis and was therefore relieved to be able to talk to medical staff about her breast cancer diagnosis and eventually, her sensitivity:

I discovered the lump myself. The huge thing was I had been struggling with environmental health in total isolation and as soon as I came with a potential tumour then suddenly the whole medical system was set up. I was in tears partly with the contrast. Suddenly there was this great conveyor belt of things…it was impressive and I have nothing but praise for staff but it was such a relief…isn't it weird, a cancer diagnosis, you were relieved and could talk about it and do something about it (Ruth).

The above responses of the women to their breast cancer diagnosis showed a variety of emotional responses such as shock, denial, feeling numb or terrified or reported not taking information in - it went over their heads. Some women felt fear and anger - few were more acceptant. But as Wendell (1999) suggests in

order to navigate the biomedical world of knowledge, women need to experience some kind of transcendence of the body before they start to construct their own thoughts about the changes to their bodies. Each woman will work through this depending on her circumstances. For Example, the stage and type of breast cancer, the outlying treatment, her work and family commitments and the type of support networks (work or family) in place to aid her recovery.

5.3 Patient Support During and After Treatment

Even with extensive medical knowledge, Elizabeth (a GP) reported that she just went with what her consultant suggested because she feared she would not be around for her children:

> I was happy to just go and have done to me whatever needed to be done. It was a really hard time because it just really sunk home then that this cancer was bigger than we had thought and it was a much more radical operation. Part of me went slightly into denial that just sort of detached myself I suppose from worrying about how it was going to affect me long term because I thought, I have just got to get this done. I had this vision of not being around for the kids and I thought I will just go through whatever you tell me I've got to have done (Elizabeth).

In her role as GP Elizabeth was used to dealing with breast cancer patients. However, when she developed the disease herself she was able to empathize more with her patients as she states:

> As a GP you get sent a letter every time someone has a day attendance at the chemotherapy unit…you sort of just quickly tick it and file it…I now think, what sort of awful week are they having and how are they going to feel a few days later, and it does make you much more aware of what's going on in their lives (Elizabeth).

Some women experienced being medicalized through the trauma of events after diagnosis:

> Getting the results and being told it is cancer and at that point they thought it was just going to be a lumpectomy. You suddenly feel you

are caught up on this sort of treadmill, suddenly your whole life gets taken over by investigations and appointments (Pauline).

Although most respondents reported being happy with the support they received during treatment Tracey, a teaching assistant, diagnosed at forty nine, was not able to explore her breast cancer experience fully:

> I think you do get fantastic treatment especially walking around the hospital with a bandana, you are just the queen of patients…I had old ladies holding lift doors open for me…it is a condition that is so visual, people do respond to it. But then you become a normal patient and that involves the quality of the communications from the hospital doctors…it's like it's been covered, it's been done, you know these are all trivial questions. What they are saying is that you are still worried about this and you need to calm down. Don't worry if your head feels a bit strange (Tracey).

Tracey tries to describe to the hospital doctor how she felt after treatment but is shut down and made to feel like her questions were trivial. Even though her "head feels a bit strange" there was nothing to worry about - she needed to calm down because the doctors have covered everything. Tracey was not able to explore her breast cancer experience fully because her questioning was halted abruptly. Within the medical models of health care, patients are either ill or healthy and since Tracey had gone through treatment for breast cancer she was considered no longer ill. But evidence suggest that the effects of breast cancer may not necessarily stop after treatment finishes as Louisa experienced.

Louisa worried for a whole year after diagnosis.

> How do you know if they got it [cancer] all, particularly because after the surgery they rang and said I'm really sorry but we didn't get a clear margin and called me back for further surgery and then they changed their mind…that didn't instill a great   deal of confidence in me…It's been awful…I got really thin – I was stressed out the whole year…I didn't relax until I had that first year mammogram. When they said it was all clear…I was convinced it wouldn't be…I just cried (Louisa).

Pauline talked about the psychological effects of finishing treatment:

> While you were being seen by all the professionals you just went along but when the treatment was finished you felt worse because you were out on your own…every ache you got, every pain, you thought has it moved? You were almost scared to live again (Pauline).

Glenda, a retired teacher, diagnosed at fifty one for the first time, then subsequently again at fifty four, fifty eight and for the fourth time at seventy, was suffering from shock on her fourth diagnosis:

> The doctor…she was lovely. She said, not only am I treating you for the trauma of it [the cancer] I am treating you for shock as well (Glenda).

Laura, a GP, diagnosed at 42, with metastatic breast cancer reported:

> I think they assumed it might have been another primary so they said we are going to have to do a mastectomy and I said right, okay, fine, I just want to go on holiday. I thought I have got to say goodbye to this breast, all these things that women do, and goodbye to my shape. The surgery had been very non-invasive, you wouldn't see the scar…you could not tell there was anything to show that I had had breast cancer at all, physically in any shape or form. Although I could have a reconstruction I hadn't got a nice bit of tummy to work on so reconstruction was not going to be easy unless I wanted to have an implant. So I had almost come to the conclusion that I would just not bother but when I came back they found I had secondaries on my spine and my lung (Laura).

The women's different occupational statuses clearly impacts on their experiences. Laura and Elizabeth's professional status enabled them to mobilize the different forms of capital they had. But to what extent does the lack of capitals possessed by Pauline, Louisa and Tracey affect their ability to resist or accommodate the dominant medical practices? Bourdieu suggests that a person's accumulated types of capital defines their life-chances or privilege (1977). As GP's, both Elizabeth and Laura had shared understanding and the confidence attributed to their medical experience and qualifications. Quite possibly, their social capital also in terms of connections with other doctors, would have meant that they would have the means to be able to negotiate treatment on their own terms. Laura states:

By then I was very holistic in my approach and I said look, let's just monitor things, let me take it on…and he said fine. I didn't want to go through the sort of chemotherapy regime which I had done before. They bombard the body with chemo and it was quite taxing. I lost my nails, we all lose our hair but you know, physically it dented me a bit. I was determined second time around that I would have some choice and that it would be looked at and it wouldn't be a knee jerk reaction from the oncologist to what I had. It was the same oncologist that dealt with my primary. Dare I say, he was a bit more open to a slightly more holistic approach. I trialled a new drug and very quickly started to get results, tumour levels dropped to completely normal levels. (Laura).

In the above case, the relationship between Laura and her doctor also supports the notion of changing professional-patient relationships in which Nettleton (2006, p.163) describes doctors no longer exert control over their patients, but rather:

they are more likely to encourage their patients to voice their opinions and to take responsibility for their health and make decisions about the direction of their treatment regimens.

Laura's own cultural capital is likely to be a factor here, but also important are the changes and influences in the past decade of feminist campaigns in women's health, disability rights, and patient groups becoming involved in primary care. Historically, feminists have struggled to intervene in debates about issues such as radical mastectomies where for many years, women were left deformed in the chest area[28] and have been victims of a "patriarchal world and a heterosexist health system" which still needs to change in terms of current medical thinking" (Wilkinson and Kitzinger 1994, p. 138).

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[28] See Leopld, E. ((1999:272) *A Darker Ribbon Breast cancer, Women and their Doctors in the Twentieth Century* for an account of the power relations which existed between doctor and patient but also the wider social relations which impacted the lives of women with breast cancer.

5.4 Resisting Dominant Practices of the Medical Profession

This section looks at the ways in which some women resist the dominant practices of the medical profession as they travel on their cancer journey. Women construct their own ideas about the disease. Their knowledge may have come about through personal experience of the disease, through family history/friends, charities, blogs such as those run by Macmillan cancer support offering patients a chance to share their experience or research the subject for themselves. Some women are offered support after diagnosis and during treatment through different breast cancer groups run by different charities. There are many different types of supporter groups, some work alongside mainstream medicine campaigning for more research, better treatments and detection advising women to have regular mammograms whilst others campaign to stop breast cancer before it starts adopting the precautionary principle of *primary* prevention. McCormick (2009, pp.14-15) suggests:

> The majority of work around breast cancer goes into improving detection and treatment and to finding a cure…while data show that getting a mammogram extends women's lives…some breast cancers do not show up on mammograms [which] miss 10 -25 percent of tumours.

McCormick (2009, p.19) cites Glasser (2004) who states, "prevention comes secondary to just keeping people alive" but at what cost? Women's work and family life is disrupted as breast cancer does not disappear quickly and there is always the danger that it can reoccur. Most clinical measurement of survival rates only take a five-year period to show the successful outcomes of breast cancer treatment. The statistics for women surviving the disease after five years are hard to find. However, the following example shows how Glenda's survival has exceeded the five year period but she feels annoyed because she is careful to lead a healthy lifestyle only to experience the return of the disease,

> What has really annoyed me, I've done everything they tell you on the cancer thing – all the five things and more[29]. I try to make the whole house chemical free, I use chemical free body care – everything you can think of and dust and so on…that's why I am so angry. I am angry about Cancer Research (UK) because, how many years have they been doing it and they still don't know (Glenda).

With no known familial history of the disease Glenda developed breast cancer four times over a twenty three year period. Her teaching career was severely disrupted each time and she was prematurely retired after her third re-occurrence. Since then she spent many years working as a trustee for a breast cancer charity promoting the primary prevention of breast cancer. She strongly believed that the reason her breast cancer returned was due to environmental factors outside her control and this led her to research and gather information about pesticides and chemicals which might be linked to the disease. Glenda spoke to many women at trade union and political conferences and has spent the latter part of her life campaigning for research on primary prevention rather than relying on cures for cancer. When she was diagnosed for the fourth time at 74, she expressed her anger to the surgeon when he suggested further drug treatments:

> Look, I am not taking any of those awful drugs…you give all these older people these drugs and it takes away their quality of life – that's the point…I'm not going to be one of those, I want quality of life. That's when I decided, No I'm not taking it (Glenda).

Glenda questioned why she had had a return of breast cancer when she had done everything she was supposed to do according to the advice from a mainstream cancer charity. She had had regular mammograms and was careful about her diet but it was not enough to stop her getting breast cancer. Glenda's thoughts on breast cancer occurrence conflicted with the medical model of care and incorporated wider social factors such as the use of chemicals and

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[29]

http://publications.cancerresearchuk.org/preventionhealthylifestyles/generallifestyle/healthydl.html

pesticides. She considered her home to be chemical free and was adamant that she did not want to expose her body to any more toxins when the surgeon recommended she must have more treatments - she was aware this would affect her quality of life. Many women like Glenda question why it has become standard medical practice to rely on mammograms and that breast cancer is seen as an inevitable disease for women. It seems to me that if a significant percentage of women are missed through mammograms then it is not an accurate prevention method that can be replied on.

Rosemary, a doctoral researcher, diagnosed at twenty nine, was pregnant and refused to accept follow-up treatment after surgery which her surgeon advised.

> I was told I would have to have an abortion as the treatment would affect the baby. I said I would not agree to an abortion and I only wanted surgery to remove the cancerous lump. I would not agree to any further treatment, either radiotherapy, chemotherapy or hormone treatment. I went with my gut, my intuition. The Macmillan nurses were amazingly supportive through the whole process (Rosemary).

Rosemary also reports:

> A lot of black women are very hesitant to approach their GPs fearing that we are going to be faced with this stereotype of our race. I'm not sure whether that's the case but it is a barrier. Quite honestly, I don't think they understand. If he had his way he wouldn't have sent me to a specialist. He saw it as a waste of time. And they say that black women don't use these services. But when we do go – a lot of black women I know, my friends, we feel that we are not taken seriously so if you are going to go and have that attitude back, you will probably wait and not go and then it becomes aggressive (Rosemary).

Rosemary's case demonstrates the power dynamics between surgeon and patient. Initially, she felt disempowered due to racism and sexism. The surgeon did not consider Rosemary's wishes to protect her unborn child and have minimal invasive treatment as an option. She was 'told' she would have to abort her child in order that she could then have treatment for her breast cancer. As far as the surgeon was concerned, his focus was on the dysfunctional part to be fixed

(breast cancer), not the unborn child. The surgeon's advice was expected to be followed.

The surgeon heads a team of health professionals who are made up of middle class, almost entirely white English and predominantly male which is very different from general practice where it is usual to see predominantly female, Asian and other migrants and is considered as lower status. Raghuram, Henry and Bornat, (2010, p.8) found that although migrants can "participate in non-migrant elite networks" they are limited in their ability to convert this into economic capital in terms of employment which Bourdieu (1986) believes is controlled by regulatory practices of non-migrants. The relationship between the GP and the surgeon will be fraught with all sorts of issues which not only involve professional status but also intersect with ethnicity, gender and class.

Generally speaking, when rights and duties underpinned by a set of social norms and values are established within a dominant medical model it is difficult to break with tradition and change the way these hierarchical relationships work. In 1951, Parsons stressed the importance of the doctor-patient relationship to illustrate how the wider social system applies to health. He states there is a need for a reciprocal but not equal relationship between doctor and patient if the patient is to get well (Nettleton, 2006, p.139). From a functionalist perspective, the power still remains in the hands of the doctor (ibid). Patients are expected to use their initiative about whether they need to seek medical advice but, "they must defer to the doctors' judgements and interpretations. Thus, the patient is placed in a 'double bind'" (Nettleton, 2006, p.141). Although there is less of a hierarchical difference in the relationship between GP's and their patient compared to the surgeon and patient, there are still barriers to health which are intersected by ethnicity, gender and professional status.

However, Rosemary was far from passive and went with her intuition to have just surgery. Fortunately, she was supported by Macmillan nurses who are a part of the support team although further down the hierarchy in terms of professional

status and although they work in the context of a medical model of care, they are more likely to have discussions with patients about the type of support needed to facilitate their decisions even if they are contrary to what the surgeon has suggested. Similarly, Glenda had strong beliefs about breast cancer treatment and challenged the surgeon's treatment plan on her fourth occurrence. It is difficult to establish whether or not these two women's professional status (capitals) impacted their decisions about treatment outcomes, giving them the power to resist this particularly medical model of health care. Both women knew how they wanted to proceed from the time of diagnosis and it may well have been their insistence that helped them carry out their plans.

Differences in the way in which people resist dominant medical models of care not only exists between patients but also between health professionals. For example, the recommendations from Pat's oncologist seem to support the idea that not all health professionals think exactly the same way even though their training comes from a medical model under which they are expected to work. We cannot say that there is only one medical model but the narratives suggest that there exists a model which is very powerful in how it affects patients. It appears that the model is less monolithic and more flexible than at first glance.   It might simply mean that some doctors, surgeons in particular, do not look outside their specialism which demands that they retain a narrow focus.

After initially being told she would have to have radio-therapy, Pat decided against the treatment after much discussion and acted on the advice of her oncologist who stated:

> I really don't recommend it…it can scar the lung, if it's on the left side it can affect the heart and you could have heart trouble in the future (Pat).

In this instance, Pat's health professional is taking a more holistic approach by entering into dialogue with her patient and involving her in her own care. Nettleton (2006, p. 137) states,

> Most people are able to develop sophisticated accounts of health and illness…they play an important part in interactions with trained health care workers…the quality of interactions affects the outcomes of health care. Such outcomes include the extent to which a patient recovers from an illness…or the level of satisfaction with the health care provided.

Linda, a care officer for an NHS Trust was made redundant the day before her diagnosis at fifty three. She used her medical knowledge to carefully consider advice about treatment. She also listened to what her body was telling her about taking hormone therapy:

> I looked at that [information] and I discussed it with the oncologist, discussed it with the breast surgeon and then listened to what I was feeling in my body. My head was telling me that, more than my body. I made a decision based on facts as well as feelings. I suppose some women would have been so frightened, worried that they would just take anything (Linda).

Similarly, Evelyn also had some knowledge of physiology through her work in alternative therapies and understood what it meant to have lymph nodes removed:

> Luckily all the lymph nodes they removed were cancer free which was really good news. I had already studied for body massage and aromatherapy and knew how they operated so I understood all that prior to their removal (Evelyn).

The following two patients were not so fortunate in having their medical needs understood or met. Janette, a county council officer, now unemployed, diagnosed at forty three, struggled to make her voice heard with regard to her health needs. During her treatment, there were important factors which she states were not considered important at the time:

> The first surgery knocked me out for two months, the second surgery I was knocked out for three months. I am very sensitive to any opiate based drugs. I lost several days to sickness and being bed-ridden…I couldn't cook or shop for myself and get it at the time I needed to eat.

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I would have really struggled if I had been on my own at that point. I didn't have much choice…I had to stay with family. I think they [doctors] just took it for granted that if you get through chemo then radiotherapy was a walk in the park. The impact of radiotherapy wasn't discussed with me and I wasn't given the opportunity to so no. By the time I had finished Herceptin my heart function had just taken its first dip and they said, 'there is nothing to worry about…it is within the realms of normal' I thought I would be able to go back into the gym but no way because the radiotherapy started to hit so it was quite demoralizing really. I am gluten and lactose intolerant…most of the drugs given to me had lactose in them. I had to badger and research to find a lactose free. I had a liquid form of tamoxifen which tasted disgusting…there is still a certain smell or taste that I physically recall (Janette).

Ruth reported a lack of awareness amongst medical professionals of her underlying health problems:

I had a very rough time on the chemotherapy which was realised that the combination of the day time electromagnetic problem and the chemo, my body couldn't cope with the two together. There is a lot of research but as soon as you mention it to someone who is hearing about it for the first time, it turns heads. When my husband got daytime shielding around my chair, my chemotherapy normalized (Ruth).

Access to medical information was sketchy for some patients like Tracey who was interested in knowing statistics for survival rates:

I went on-line and thought, Oh, that's not as good as I was hoping for. Five years is good but ten years is sort of variable between…I think 65% was the lowest number I came up with…that's not enough, I'm not happy with that. What the consultant did say is, we could give you a number say its 75%, you still don't know if you are just outside that (Tracey).

Getting the right support was difficult for Janette and Ruth and Tracey needed information to reassure her about survival. Jones and Greenwood (1994) looked at causes of distress in breast cancer patients and found that fear of recurrence was one of the highest factors affecting women.

During an International Symposium on Breast Cancer and Feminism (2015)[30] Ana Porroche-Escudero highlighted how campaigns were used to persuade women to comply with biomedical recommendations. Misleading information and also exaggerating data on incidence, mortality, survival, and treatment efficacy was given to women. Another speaker at the conference, Julia Ojuel, a GP and co-founder of Cancer Butch with a PhD in statistics, warned:

> Much information about survival, prevalence, and mortality to promote breast cancer screening is taken for granted by many health professionals and organizations. There is a widespread tendency to assume that the scientific facts both 'speak for themselves' and are bias free.

In addition to women's fears about survival, breast cancer patients are under pressure to regain their 'natural' feminine body - removing a breast is considered a threat to women's feminine identity which is constructed early in childhood and well before women face breast cancer. The following section explores how women cope with the changing body after breast cancer.

5.5 Body Image

After mastectomy the breast care team work to get patients 'back to normal' by offering reconstructive surgery or by encouraging the use of a prosthesis to give symmetry. This normalizing exercise, they believe, is part of the expected route through breast cancer. Pauline was told that she fitted the criteria (age 53) of having a mastectomy and reconstruction but it had to be done within 28 days:

> He sat me down with a portfolio on the computer, pictures which I found…I just cried my eyes out. I had never seen anything like this before only when I think of someone having a boob job. It's someone that has these gorgeous looking breasts. These were of women who had got one breast okay and the other didn't match. And it was as though they were supposed to be really, really good but to me they looked horrific and I felt so bad. I felt so guilty for what I felt (Pauline).

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[30] Ana Porroche-Escudero (Lancaster University and Breast Cancer Consortium) was co-organiser of the symposium held in Barcelona, Spain on 9 April 2015.

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Even after five years Pauline says she still remembers this traumatic experience of being shown images of a breast reconstruction that did not match and looked "horrific". In the eyes of the surgeon, the main objective is to return the patient to what is deemed as a 'normal' female shape. The constructed breast like the prosthesis is hidden from view inside a bra. However, body image to the patient is an important factor which cannot be just hidden away or forgotten. The personal loss of a breast for some women is like losing a limb – one has to mourn the loss, learn to accept this loss and re-gain confidence in becoming a one-breasted woman. Bouquiren et al (2013, p.2178) state that body image is

> conceptualized as a multifaceted construct, defined as the mental representation of one's body, thoughts and feelings about one's physical appearance, attractiveness and competence, as well as one's perceived state of overall health, wholeness, functioning and sexuality[31].

Lorde (1988, p.33) who was normally a strong and confident woman describes how she felt vulnerable after her mastectomy:

> …not even the most skilful prosthesis in the world could undo that reality, or feel the way my breast felt and either I would love my one-breasted now, or remain forever alien to myself.

Furthermore, Lorde (1988) describes how women are denied the opportunity to explore their own experiences no matter how hard and painful those experiences are. They are encouraged to 'move on' by accepting the constructed meanings of the post-surgical "mastectomised body as unfeminine, abnormal and desexualised" which Crompvoets (2006) believes is promoted by mainstream breast cancer culture. She stresses the importance of how "gendered emotions are publicly mobilized and performed" by these movements that promote the "science and medicine and the workings of power…" (Crompvoets, 2006, p.67).

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[31] Within Gender-role socialization, a strong psychosocial factor which is believed to influence body image is the standards regarding physical appearance and behaviour. These are strongly influenced by media images of what become known as cultural norms which women adopt in order to gain approval from family, friends and from society at large. (Boquiren et al, 2013:2178).

Pauline demonstrated how gendered emotions affect how women see themselves after surgery:

> I had already had ovarian cancer three years before breast cancer. I can remember thinking that if I ever got breast cancer I would die with it because I wouldn't have had what I classed as a female body. Having already lost one bit…if they took away my breasts, then what was it about me that was female? (Pauline).

Glenda also complained that being treated with anti-hormone drugs four times for breast cancer, she was not only left with no breasts but "with no vagina – tamoxifen has dried it all up".

Breast loss for Pauline and Glenda constituted loss of feminine identity and this distortion is a "constant reminder of the relationship of the body to self-image, gender identity and sexual expression" (Thomas-MacLean, 2004 cited in Manderson and Stirling, 2004, p.76). Henson (2002, p.271) reports that sexual dysfunction after breast cancer is not well documented. The impact does depend on the patient's age and what treatments they have had but that:

> Younger women have greater difficulties with altered body image, change in reproductive capacity, and altered sexual function especially if they place a high value on breast appearance and sensation or are subject to early menopausal hormone flux. Patients who have received chemotherapy appear to have more fatigue, more vasomotor side effects and more general sexual difficulties. Induction of premature menopause as a result of treatment can result in an oestrogen deficiency that increases the likelihood of poor vaginal lubrication and vaginal atrophy that may in turn lead to sexual dysfunction.

Normalizing the female body by offering reconstructive surgery was not without its problems for the informants. Rachel, a teacher, now unemployed was first diagnosed at forty six but the cancer returned:

> It came back and it took them a while to find it because it was underneath the reconstruction. So it re-occurred on the same side and it was a full reconstruction but apparently that had gone really yucky with the silicone. It was at the time when all the problems were reported

about silicone implants. It had really deteriorated so they removed it and the underlying cancer as well (Rachel).

Spence (1995) stated that women have to find the language to express their feelings about breast cancer and Lorde (1980) suggested women should join together in support of the mastectomized body and become more visible to each other. More recently, Cristina Vela brought together the work of national and international artists at a symposium to show the realities of breast cancer in Spain (2015). These images portrayed women and men who had undergone radical mastectomies which challenged taken-for-granted assumptions and showed how women can come together to make social suffering more visible. However, these opportunities are rare for women to express themselves and are mainly confined to academic audiences or through the medium open to artists.

For some women body image problems included increased weight gain following breast cancer treatments which most women say is not discussed during treatment options. Janette reports:

> I really started to stack the weight on…Nobody had discussed weight gain…I was physically very fit before this. I have put on two and a half stone just as a result of the drugs. The Herceptin made my knee joints and my ankle joints puff up and swell. Whilst I was on chemo I would say, 'I'm really huge' and they would say 'no you are not really'… (Janette).

Janette declared that she was physically fit before her diagnosis and was competing for Great Britain as a dragon boat racer. Nobody had talked to her about the possible weight gain or the after-effects of radio-therapy. Losing her fitness was hard and caused her stress. But because she was aware of her body's capacity to act she had the knowledge and the determination to fight to 'get back into the boat'.

Body image and sexuality were important factors to Janette:

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There are all sorts of gender issues linked in here as well – being a lesbian and having a double mastectomy I went from a large breasted to hollow chested to now. The first time I actually felt total acceptance was when I was with a lot of fit athletes and they have virtually no boobs anyway. And I thought, all I need is a pair of nipples and by that time I did have latex nipples and I thought 'wow, I fit in here – I'm great'…I know I can work my muscles now and they are responding in a more normal way…my weight is going now and I link that to diet – refined sugars and foods I have cut out and I know I react badly to…it is an absolute maze of work but it is quite interesting because it gives me knowledge (Janette).

Another considered feminine trait valued by some women is their hair. Having to have chemotherapy for most patients means losing their hair. Although most patients dread the loss of their hair, Shirley, took practical steps to prepare for this loss:

Somebody told me not to have the cold skull-cap because you still lose some of your hair…and I thought, if I am going to lose it I don't want to look like a 'mad women' and my best friend was a hairdresser so I said to her because it was shoulder length, can you cut it in like a page boy style? I thought no, I'm okay…hair is hair…I know it is going to grow back. I lost the hair that week in hospital…it was coming out in clumps so I said can you shave it off. I had a wig but didn't really like it…my son used to call me baldy (Shirley).

Ucock (2002, p. vii) reminds us that "appearance is more than just an expression of self…it constitutes the self, or a part of self". The loss of hair and the breast just adds to the uncertainty of identity and to survival. Pat reports:

I was going to have this icecap to try and save my hair…I have got a lot of hair but it went particularly thin…I don't think the first hat particularly fitted well… and I lost hair from the hairline which is coming through very finely now. (Pat).

Both Pat and Shirley were concerned about their appearance and how they would look when they lost their hair. Ucock, (2005, p.291) pointed out that "In addition to the fear of dying from breast cancer people fear the effects of their bodies"

Although Evelyn was not in a relationship at the time she considered what might lie ahead. Her age and sexuality were important to her:

> even though I was 57, not in a relationship I thought I would still like to feel feminine – you look ahead and think well if I ever did meet somebody I would still like to look normal…things like going swimming – rather than have the trouble of having a prosthetic so I went down that route. I was given the choice of an uplift on the good breast: he said 'would you like to be balanced while you are under the anaesthetic? It pays to lift this one at the same time as when you put the reconstructed one in'. So I opted to have that one done (Evelyn).

Evelyn's femininity is important to her and every effort was made by the surgeon to normalize the diseased body which the above case shows. Women who have had breast cancer are "marketed, represented, advised and spoken about" and this impacts the way they want to be seen and also how they want others to see them (Crompvoets, 2006, p.22).

5.6 Conclusion

The above extracts from women's stories show how breast cancer patients construct personal narratives of the disease according to the context in which they are placed and how, in some cases, these contrast with dominant medical ideologies and models.   Many women feel the shock of diagnosis although they cope in different ways with the aftermath of the diagnosis and treatment. There is disruption to their lives and for some the suffering is long term both physically and mentally, especially where breast cancer returns again and again. For some women the fear of the disease returning creates on-going anxiety and stress. And for one patient it was a relief to have a diagnosis of breast cancer which finally brought her existing health problems into view: sensitivity to electromagnetic fields which she struggled to have acknowledged as a medical problem.

For many women, the relationship with their surgeon is important. Firstly, patients need to have faith that they will be cured and survive breast cancer. There are many different hierarchies and differences in the medical profession with surgeons being of the highest status group, they are most often white, middle

class (Raghuram, Henry and Bornat, 2010, p.8). Stacey contends that one of the main objectives of the GMC when it was founded was to:

> convince the public (that is men) that they could trust registered medical practitioners to treat them appropriately, including entrusting their wives to their care…to achieve the upward mobility of medical practitioners so that they might be accepted as gentlemen (Stacey cited in Wilkinson and Kitzinger, 1994, p.193).

Secondly, currently literature shows that women with breast cancer feel they need to claim back their lives and move on. As part of their returning to 'normal' some women are pressured into thinking that they need to be restored to an acceptable body shape. Women who suffer breast loss are more often than not, persuaded that they need to wear a prosthesis or have some type of reconstructive surgery in order to get back to their 'normal' feminine self. Outwardly, they may be normalized but inwardly they may never resolve their experiences of loss. Crompvoets (2006, p. 66) believes "The post-surgical body in mainstream breast cancer culture is by and large shrouded in secrecy, something to be covered up and not spoken about".

Thirdly, most breast cancer patients are encouraged to adopt a positive attitude which is part of cancer advocacy as the only way forward – a process which all cancer specialists try to instil in their patients as part of their wellbeing. However, some patients due to continuous ill-health, find it difficult to remain positive. The next chapter follows the women's experiences as they prepare to enter the return to work process. Here they experience different social problems which are largely unmapped.

Chapter 6

The Process of Returning to Work

6.1 Introduction

In chapter five the research data highlighted how the body has become known as a complex system, which plays a number of dynamic roles in a cultural, social and economic world. My respondents' data showed how disease is managed and how the body can be constrained by dominant medical models and ideology. It also raised concerns (Glenda and Ruth above) about how one pathology affects another in the environment in which we live and work and that these factors are not taken into account when treating the diseased body.

This chapter looks at the process of return or non-return to work after diagnosis and treatment, or in some cases, during treatment. It explores women's attitudes towards work after breast cancer, their work status and career aspirations and how support networks play a part in influencing a return or non-return to work. I will highlight the importance of how women's embodied experiences are not only about immediate experiences located in a specific context i.e. RTW after breast cancer, but also how the body intersects with culture. I will draw on theories of cultural capital, gender and work, disability, illness and work.

Of the sixteen women who were diagnosed with breast cancer, twelve were in full time work although two had been made redundant one day before diagnosis. Two were self-employed/agency workers, two were unemployed due to on-going health problems. The mean age of the women on diagnosis was 45. At the time of interview, only five women who were employed full time had returned to their original jobs, one of whom returned on reduced hours. Five women changed their occupations – two became full-time student researchers. One women retired, and three remain unemployed.

6.2 How Breast Cancer Impacts Women's Employment

Because of its fluidity the body's relationship to the world is constantly changing and can, at any time, become disrupted, for example, through the development of breast cancer. Emily Martin (2000, p.130) cites Bauman (1992, p.189) who describes how these bodily flows may alter:

> A complex systems model of the body carries with it the possibility of catastrophic collapse. Since in complex systems, slight differences in initial conditions can have magnified effects, and since such systems contain randomness and disorder within order, what order there is local, transient, emergent, like a 'whirlpool appearing in the flow of a river, retaining its shape only for a relatively brief period at the expense of incessant metabolism and constant renewal of content'.

Martin (2000, p.141) further adds, just as Bauman suggests that bodies are in a constant state of flow, so too the processes of labour demand the same system of flow and flexibility that are required of us if we want to participate fully in work:

> Flexibility has also become a powerful commodity, something scarce and highly valued, that can be used to discriminate against some people…At issue is what kinds of bodies we imagine will be able to survive the present or next wave of downsizing.

If workers are required to become flexible in their work habits then this creates additional problems for women who are forced to take time out to recover from breast cancer, particularly if their work contracts are not secure for instance: redundancy, zero-hours, self-employed, agency or part time. An additional burden for women is the attitudes of some employers towards working with breast cancer as Cathy et al (2002, p.1310) cites studies that show, "Employers often fear that cancer patients have lower job performance and productivity and higher absenteeism" (McKenna 1987) and in some cases there were reports of "discrimination on the part of employers" (Carter 1994; Berry 1993). This is supported by Macmillan (2013) in their recent research which reported "almost four in ten people (37%) who return to work after cancer treatment say they experience some kind of discrimination from their employer or colleagues – compared to just under a quarter (23%) in 2010".

Furthermore, in this new flexible way of working according to Martin (2000, p.141):

> …certain categories of people (women, people of colour) will be found deficient. Particular social groups may be seen as having rigid or unresponsive selves and bodies, making them relatively unfit for the kind of society we now seem to desire.

Martin is suggesting that alongside this new flexibility the body is also constrained which is critical to breast cancer survivors if, as she says, "they cannot stop moving, they cannot stabilise or rest, or they will fall off the 'tightrope' of life and die" (Martin, 2000, p.143).

For some women, career aspirations change after breast cancer whilst others face limited options for a RTW. I start by exploring five cases where respondents were faced with decisions about taking different career paths after breast cancer diagnosis for a variety of reasons.

6.3 Choosing a Different Career Path

The first respondent had been a Performing Arts lecturer at a college for 12 years and suffered bullying during a programme of restructuring and redundancies and after she reported that she would have to have time off for treatment for her breast cancer. She witnessed unfair treatment of her colleagues, some of whom left because they were bullied. Accusations were also made about her work performance which, on reflection she said were tactics to push her out. Her attempts to seek help from her union rep failed to materialize. She reported many members leaving and the union was rendered ineffectual and so she found herself unrepresented at meetings. She felt unsupported by HR and had to deal with the situation on her own.

> I had come back from cancer and at this stage they [employer] then knew that I was going to have to go off with breast cancer and what they [the doctors] thought was also Hodgkin's disease at the same time

and I'm thinking, this is desperately wrong, this is desperately unfair… how can she [line manager] be allowed to say things like this. I'm being bullied here and their [employer] stamp is on it as well by saying if you want to take this further then you take this further. That to me seemed so wrong. I felt so totally unsupported and totally and utterly on my own (Rachel).

And at a later meeting with management again she felt totally unsupported by HR and management when further accusations were made about her work performance.

There were three of them (HR and managers) sat there with me in the corner and they were telling me all these vile things about myself and I am doing my best to defend it. I asked them for minutes of that meeting but there were no minutes. I should have followed it up and all the other things I should have done (Rachel).

At a final meeting with HR Rachel reported:

To be honest I've just had enough and she (head of HR) said well hang on, don't go without anything. I hadn't actually said I've had enough and I'm not coming back here ever again but it was obvious she was offering me redundancy (Rachel).

Rachel left the college and became a full-time MA student whilst she was still going through treatment. She suffered from depression which she believed had more to do with her experience of bullying rather than the tablets she was on for breast cancer. She considered that the bullying affected her more than the cancer:

To a certain degree I think it was worse than the cancer. When you are going through cancer, it's well…here I am and I'll get through it…now I have time to lie around and I don't have to go to that terrible place for work and people are being very nice to me and bringing me flowers (Rachel).

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Rachel's case demonstrates there were no systems in place within the college to assess how she was coping on her return to work. It appeared that management had little or no experience in dealing with cancer patients. There was no discussion about a phased return when Rachel came back from her treatment for Non-Hodgkins disease, nor were there any meetings to monitor her work ability. She was left to get on with her work and then criticized for her performance when she could not cope. There was no support from HR and no union support available, so Rachel experienced the result of how illness intersects with poor work relations and stated that "the bullying affected her more than the cancer" (Rachel).

Williams and Busby (2000, p.170) refer to the work of Shakespeare (1977) who suggests "culture and experience remain central to understanding illness and disability" and that there is evidence enough to suggest that "unremitting socio-economic stress [can have] biological effects (e.g. endocrine and immunological disorders)" (Williams, 2000, p.304). Rachel not only faced these biological disorders within her cancers, but she also faced losing her job. Williams describes the effects as important key issues and which could be applied to Rachel:

> Feelings of stress, hopelessness, depression, loss of a sense of coherence and the dilemmas of insecurity and control. These and many other factors have been shown to be associated with higher levels of mortality and morbidity (Williams, 2000, p.304).

Shirley worked as a post office manager but left to become a cleaner after a series of events that left her feeling unsupported in her job. In the first instance there were disputes over sick pay. She relied on her husband's wage while she was on statutory sick pay:

> It was tight because I was basically taking half what I normally take home which pays for the mortgage and everything. I was sending sick notes in monthly. I didn't know what was happening, one month I would get paid statutory sick pay, next month I would get paid two months

statutory sick pay and the following month I wouldn't get any money. They reckoned there was an over-payment of £1,000 which I disputed. I don't get paid a lot and asked to pay back £50 per month. They said, no because at the end of the day, you could leave the job. I said, why do you think I come back to work the week I'm actually having radiotherapy, does that not show commitment? They took the money back at Christmas! Because we were a franchised chain they could pay what they liked. I was on £6.50 an hour. Sometimes I didn't actually have any cover or any proper breaks. When I got a 10p an hour rise I thought do I really want to be here. I was responsible for tens of thousands of pounds. It's not all about the money, it is about paying for what you are worth. The cleaning job I do now you know, I like to do a good job, it was just the way I was brought up (Shirley).

Shirley worked through chemotherapy and radiotherapy treatments making sure the appointments were outside her working hours. She didn't know that she was entitled to have time off work for these so made them in her own time. She was not told that she would be allowed time off for treatment.

Because work is an important factor in regaining a sense of normality many women try to work through treatment. There have been few studies researching a RTW during treatment but Shewbridge et al (2012) found forty-four percent of respondents worked during the start of their chemotherapy but this figure decreased during the latter stages of their treatment. They found that initially employers were supportive when treatment began but as the treatment progressed they became less supportive. The authors recommended interventions to support patients working through treatment and that:

> Health care professionals need to gain a better appreciation of the importance of work in patients' lives and to explore the meaning of work for them and understand a patient's needs and wishes with regard to work during treatment (Shewbridge et al 2012, p.121).

However, if employer support lessens as the treatment progresses, what happens if treatments are prolonged for any length of time. These narratives suggest that employers need to better understand the problems women face returning to work during treatment but that employers should discuss what women need in order to be able to return.

In Shirley's case, there was no discussion of a return to work plan which incorporated treatments, there were no adjustments to work patterns and no information given to her about benefits or that she was entitled to attend treatments with pay. This suggests that all employees should be given clear policy guidelines in work places and offer support to assist managers understand what these are too. "Looking after oneself" was reported in Shewbridge's study as one of the most important factors for women returning to work but if employers are to act, as Blinder et al. (2012, p. 768) suggest, as the "gatekeepers who permit the breast cancer survivor to have flexibility in her schedule, adapt to the demands of work, maintain her privacy and preserve a 'normal' environment at work" then they must be held responsible for facilitating a safe return.

Linda, a department head for an NHS Trust, diagnosed at fifty three, changed her career path for different reasons. A friend suggested she think about her breast cancer experience and her relationship to work:

> well it's going to be difficult for you to get a job…you only have to tell somebody that you have had cancer and they might not want to employ you because it might make them anxious about taking somebody on like this. I had never thought about it and it shocked me to the core that she had actually said those words to me. And I got home and I was in a dreadful state about it. It had never crossed my mind that anybody would think that way. Once she said it I did start thinking about it and relating on it. It could be the case here…maybe they would because I am a mature woman and maybe they would see it as…you know, not a very good recruitment choice. I did get in a pickle about it and it put me off (Linda).

She applied for jobs and got interviews but then she realized she wasn't ready mentally to go back to work. It was during research for her Masters dissertation on transition and change that she realized that redundancy and breast cancer were a catalyst for her mid-life crisis. For two years she was unable to make decisions. Linda was in a senior position in the NHS but was made redundant just before being diagnosed with breast cancer. She states:

>I felt as if my life was on hold. I didn't have work and wouldn't have been able to apply for a job…what would I have said? Sorry but I can't commit to anything because I have just been diagnosed with breast cancer. It did stop me moving forward but I suppose I was lucky I had all my redundancy money and didn't have to worry. What happens if somebody is not in that position? I don't think anybody would have taken me on having to lie…I had to have an operation then I wouldn't have been able to drive for 6 weeks after the radiotherapy. Because I didn't have a job to think about going back to, real depression set in…I had to take anti-depressants. I started really grieving the job I had lost after 14 years. I practiced mindfulness and trained to become a mindfulness teacher and it's the best thing I have ever done (Linda).

Linda finally took a job as Chief Operations Officer for a care group which she says:

>has brought together all the skills and all the learning that I have done over a life-time…I am in the right place…but It has taken me nearly two years to get here (Linda).

For Linda, a positive change facilitated by her response to breast cancer, helped change her career path. However, getting through depression after breast cancer is not easy for some women. The impact of breast cancer is not necessarily short-lived or confined to the physical body. Depression affects many women after surgery and treatment and can affect psychological wellbeing which can last for years, as in Linda's case. Bennett et al (2006, p.1) suggests there is a "close relationship between cancer related fatigue (CRF) and diagnoses of depression or anxiety disorder" but there is limited information about these effects over time.

Studies have shown various reasons for retirement or non-employment after breast cancer. For example, Lindbohm et al (2013, p.638) [32] found "Depression is a known reason for disability pension and was also related to early retirement" [33]alongside other barriers to a RTW such as: "older age, low education, low

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[32] See also Suppli et al.(2010), Vin-Raviv et al (2015) for depression in breast cancer patients and Jae-Min Kim (2013) for suicide in breast cancer patients.

[33] Macmillan Cancer Support in their report "Worried Sick: The Emotional Impact of Cancer", state three quarters (75%) of people who experience depression do not receive information, advice, support or treatment for it.

income, manual work, a high demand job, co morbidities, undergoing chemotherapy and a non-supportive work environment" as well as women's changed priorities to their health and lifestyle. However, this study excluded women over 63 or those in receipt of old age pension, women who had had a recurrence of the disease or women who were not in employment when diagnosed. In my study I considered it important not to exclude age as a variable. Some women work on well past retirement age and this age group is at an increased risk of breast cancer.[34] Anybody of working age who responded to me was included in the programme.

In the UK, approximately 100,000 women are living with a diagnosis of secondary breast cancer each year according to Johnson (2010, p.561). The category of 'recurrence' of breast cancer excluded in the above study is one that I considered essential to include in my research because it highlights that breast cancer can be long-term – way past the five-year period that is taken as a measure for breast cancer survivorship.[35] This measurement does not show the long-term impact that breast cancer has on women and work which was the case for three of my respondents. However, Shewbridge et al (2012) raised questions about work patterns over time and recommended a longitudinal study to explore women's breast cancer and work. They acknowledged the limited use of questionnaires to explore this and recommended future studies should incorporate mixed methods. I would also add to this, a multi-disciplinary research team for future studies in order that the models of health can be widened so that women returning to work after breast cancer can tell their stories. Williams and Busby (2000, p.170) cite the work of Irving Zola who advocates a more "pluralistic politics of disability, including impaired bodies and oppressive societies" which would include the workplace. Williams and Busby (2000) call for "broader definitions of

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[34] Moser et al (2007) "Do women know that the risk of breast cancer increases with age?

[35] The government's latest report "Improving Outcomes: A Strategy for Cancer" (2011p27) still shows 1-5 year measurement for survival.

rehabilitation as the restoration of patients to their fullest physical, mental and social capability" (ibid).

Sharing a similar experience to the above cases Janette, who was a local County Council officer was made redundant and left work the day before she was diagnosed with breast cancer, aged forty three. Living alone she struggled with energy and found it hard to commit to anything more than a week in advance. As well as losing fitness she lost her financial independence, both of which were important to her. She states:

> I had a small redundancy pay-out and managed to survive living at family's houses – their bills were my food bills and I wasn't driving. I was earning a very good wage before but didn't actually have any savings. Benefits wouldn't have covered a thing. I didn't have the capacity to redo my house insurance or car insurance. I had to re-do all my household bills, shaving that down (Janette).

Janette had taken out two insurance policies, one for redundancy and one for sickness. However, the insurance company refused to pay out on the redundancy policy because she was diagnosed sick the next day. It became null and void because you have to be fit and actively seeking work which she wasn't. The sickness policy wouldn't have paid out for 12 months. She reported she had

> …fallen through the gap in both policies so on the advice of a colleague I had to sign myself fit for work after surgery and I hobbled along to the job centre every two weeks and sent in job applications – three forms of evidence every week and also send that off to my insurance company. That was a high cause of stress but they started paying out the following January for up to two years (Janette).

Eventually Janette was signed off sick and received sickness benefit whilst she underwent further surgeries. As a single woman living on her own with no

financial support she felt the strain of being out of work due to the long-term effects of breast cancer and having to rely on benefits. She reported:

> I am reluctant to sign on to employment benefit because they squeeze you down a funnel and they squeeze you into this position where you have to take anything. I don't want to get stuck in a system where my energy will be zapped. I am worried about the mental impact and the demoralization, that I won't have the capacity to pick myself up and to push myself in the direction I want to go in (Janette).

Still suffering from anxiety and stress a couple of years on Janette reports:

> As soon as there is any element of pressure either in terms of a timescale, getting something completed by a certain time or having to do with money, my anxiety and my stress levels rocket and my brain turns to mash. So in terms of being able to work for somebody else in the corporate world, I just think I wouldn't be able to cope (Janette).

Janette's story uncovered many issues which women experience recovering from breast cancer: loss of identity and financial independence through unemployment, change in employment status due to physical and mental disability, unexpected long-term recovery and co-morbidity, having to rely on family and friends for support and losing confidence about a RTW. There is limited material on the long-term effects that breast cancer has on working women. Cathy et al. (2002, p.1309) examined data from a US Health and Retirement study (1999) and found that "the probability of breast cancer survivors working is 10 percentage points less than that for women without breast cancer". The authors stated, one of the objectives of The National Cancer Institute's Office of Cancer Survivorship in the US is "to develop an agenda for the continuous acquisition of knowledge concerning the problems facing cancer survivors, including the medical, psychological, and economic effects of treatment" (Cathy et al 2002, p.1309). These three areas of research are usually not combined – they each have separate research agendas which demand different methodology and priorities. Additionally, studying work patterns over a long period of time has already been raised by Shewbridge et al (2011) as outlined above. And, with the increased number of women developing breast cancer each year, it will be

difficult to get an accurate picture of how the disease impacts women's employment.

Included in my research are three women who have had a recurrence of breast cancer or metastatic breast cancer. My next respondent Laura, a GP, developed breast cancer in 2003 and has been living and working with secondary cancers since that time. She had been the financial breadwinner at the time but had felt overwhelmed by her work. Although her practice was very supportive when she received her diagnosis it was not possible for her to return to work part-time so she left the practice and eventually she received an NHS pension and was fortunate enough to have a small pension so she was in a reasonable position for a good few years following her primary diagnosis. Because Laura was at that time economically stable it gave her an opportunity to:

> …explore everything there was for myself so I looked at the environment, the whole holistic picture really…chemical, what I was doing, my emotional state, the home – was it a good environment to be in, relationships and I quickly came to the idea that I was responsible and that I couldn't blame anybody else - it wasn't my parents or my genes, it was a complex mixture of things. It is a fascinating subject but it is very individual so you can't say these are the causes because it will be different for every person which is very difficult for patients to understand. I can put myself in both categories – patient and GP, you get the drug and that's the answer rather than actually thinking on a much bigger issue. So that gave me the opportunity to start various studies, down the homeopathic route amongst other things (Laura).

However, during her exploration of alternative medicine she received notification from her insurance company that they would stop paying her pension and said to her:

> well, you're five years now, you're cured and I said I don't know you can say that I am ever cured of cancer and they said no, no, no, you haven't had any…and I said well I am still not 100% back to my normal self – I felt the chemo had affected me quite badly but as far as they were concerned I was fit for full time work. And the money was withdrawn completely within a few weeks. In order to carry on with the sort of lifestyle I have got, my horses, maintaining a fairly expensive house

and a lot   of mortgage, I had to think about returning to work more seriously. I wanted to keep my hand in general practice so I approached my local hospital about returning to work (Laura).

Laura was met by the intersections of class and age when she planned to return as a GP. Approaching forty eight she was surprised by the comment:

You are a bit old and we don't know if you would have it in you to cope with the return scheme (Laura).

This return scheme to support GPs to return to work challenged Laura

I didn't feel able to load my head with revision – in many ways I would say that my memory and things from the chemo fog, wasn't as good…I found that the harder aspect to tackle. I passed sufficiently well enough for them to let me join a practice and I had to agree to do six months of unpaid work. I worked with a very good partner who was a similar age to myself and she supervised my training – very mainstream at first but she began to understand the more holistic approach that I had. It was hard because a lot of it was videoed. I was 'looked at' the writing up of the notes, the way I approached thing – I was continually assessed and in their view, I would come up a bit short (Laura).

Laura had started her diploma in integrated medicine at the same time as the returner's scheme and felt that the field of contraception and sexual health was a reasonably straightforward field to enter. She had social connections in this area. Laura very quickly picked up the work after some training, did the faculty exams, got herself on the board and that brought in some money to keep things going. She was trying to juggle a lot of balls in the air but she developed secondary breast cancer. She was advised she would have to have a mastectomy which would again disrupt her work. By this time Laura had taken a very holistic approach:

One thing I was sure of is that I didn't want to go through the sort of chemotherapy regime that I had done which was quite taxing. So I went on a drug trial and very quickly started to get results…the tumour levels dropped to completely normal levels, all the changes in the CT scan

reverted to normal. I've been on the treatment for a year but it is still continuing. I am still trying to juggle two or three sessions of general practice but I am beginning to think about maybe doing some work from home, privately, trying to see people in a slightly more holistic way. So I am actually busy, I'm competing my two horses. I needed that time away from practice. I needed time to really understand my own physiology and my own emotional thoughts, my relationship to the environment, what I wanted out of life and you know it had huge spin offs, I had two elderly parents who I was able to nurse and be with which I wouldn't have done if I had been working full time (Laura).

Comparing the two cases above, Laura, a GP, has a sizeable amount of capital that she can mobilize compared to Shirley who is a cleaner on minimum wage. However, recent studies have shown that social capital is associated with population health (Kim, Baum, Ganz, Subramanian, & Kawachi, 2011), and older adults (Sirven & Debrand, 2012). Furthermore, Melanie Vauclair et al (2014) cites research to show that "Older people are usually seen as a low status group relative to other age groups across Western and European cultures (Abrams, Russell, Vauclair, & Swift, 2011; Garstka, Schmitt, Branscombe, & Hummert, 2004)[36]. Therefore, if older women with breast cancer are considered to be included in this social group and are more vulnerable to prejudice this could also affect their health.

As a doctor, it is assumed that Laura is likely to have considerably more economic capital behind her and more cultural capital in terms of shared understandings and the confidence she can create through having medical qualifications if we are to follow Bourdieu's concept of capitals.   Seemingly, she would also have the social capital in terms of connections with doctors, not to mention that she

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[36]

https://www.researchgate.net/publication/262884014_Perceived_Age_Discrimination_as_a_Mediator_of_the_Association_Between_Income_Inequality_and_Older_People%27s_Self-Rated_Health_in_the_European_Region

has a very expensive lifestyle – keeping horses and being able to practice her interest in competing. Compared to Laura, Shirley and similarly the other cases above, have minimal capital which they can mobilize because they are positioned differently in the field. Shirley in particular, cannot 'pass go' or as Skeggs (1997) would argue, she has 'zero rated' capital – there is nothing to move.

Shirley believes in being rewarded for the work you put in. She states, "It's not about the money" and "I like to do a good job, it was just the way I was brought up" which are part of Shirley's working class values that have been passed down through her family. Unfortunately, these values no longer have influence in today's disposable workforce. Having breast cancer, on top of zero rated capital will decrease still further, any chances of these working class women accumulating capital. And without economic capital behind them they are less likely to be able to access social capital which are resources based on network connections and membership of groups.

6.4 Early Retirement and Unemployment After Breast Cancer

The next three respondents did not return to work. Two experienced on-going health problems and were unable to work and one had reached retirement age[37] although she had been an active campaign supporter for a breast cancer charity before developing her fourth breast cancer last year.

Evelyn had worked as a self-employed agency worker for an NHS Primary Care Trust for a year until her breast cancer diagnosis and her future work plans had to change. She is a single parent and cares for her elderly mother.

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[37] This was when there was a statutory retirement age.

> The temping came to an end, I finished work on the Friday and found a lump on the Monday. I signed on to look for work on the Tuesday and thought, well do I say anything? A fortnight after when I signed on I explained to her. She said if you are diagnosed with breast cancer you automatically go across from job seekers to employment support allowance because you are ill and not seeking work. They just switch over your benefits. I am still in the same situation now (Evelyn).

As a single parent and main bread winner, the pressure was on Evelyn to find full time work:

> Being divorced you tend to try and hold on to a job 37-40 hours a week, regular income, as often as you can. I don't think I was strong enough to change to a different career even though I trained in full body massage and aromatherapy and Indian head massage and reflexology which I really loved doing. I couldn't see that income would support me enough with a mortgage, as a proper job (Evelyn)

A woman's social position and work status may affect the type of decisions made about treatment and their attitudes to work. Some individuals may find it difficult or indeed impossible to acquire capitals. It wasn't a straightforward case of just returning to work for Evelyn. Due to suffering on-going health problems including fatigue and arthritic pain she also developed diabetes and angina after chemotherapy and believes:

> Different chemo treatments can affect the heart muscle but they don't tell you that at the time so I am going down that route now. Some days I get really breathless. So my GP has put me on aspirin, beta-blockers and statins (Evelyn).

Merchant et al (2008, p.1098) report that there is an increase in the number of women living with the after-effects of breast cancer treatment. They report, "It is not uncommon for women to report shoulder and upper limb problems years after surgery, particularly when the surgery included axillary node dissection" which Evelyn experienced.

Agency workers on low pay and temporary contracts like Evelyn are exposed to precarious work patterns with little security when their health fails. This reduces

her capitals even further. The chemotherapy treatment, Evelyn believes, has affected her health and delayed her RTW. The agency she is registered with have told her to come back when she is well again. She believes that employers have a negative attitude towards you if you are not going to be there for them 24/7. This is supported by Macmillan (2013, p.1) who have highlighted that employers are failing to protect people from unfair treatment and stigma at work and are "flouting their legal responsibility". Evelyn has suffered ill-health for two years now and remains unemployed. Furthermore, as an agency worker she does not have the same protection of workplace practices which recognize disabled workers' rights under disability discrimination legislation. Currently Evelyn has zero capital.

After two lumpectomies and two mastectomies, my oldest respondent, Glenda was able to provide a valuable long-term picture spanning over twenty-three years which demonstrates how breast cancer interrupts the working lives of women in an ongoing process of disruption rather than discrete events. Glenda had received a range of treatments and different after-care support during her breast cancers, some early support enabled her to RTW reasonably quickly although her third incident resulted in her prematurely retiring from teaching due to ill-health.

Lindbohm et al (2013, p.634) found that previous studies mainly focused on cancer survivors' RTW, however "little research has been performed to investigate different subgroups of survivors outside the labour market or the factors that affect their work cessation". The authors also found depression, anxiety and fatigue were factors related to early retirement. Although Glenda retired early from teaching after she was diagnosed at the age of fifty eight, she worked tirelessly as a trustee for a breast cancer charity and actively campaigned for a focus on the primary prevention of breast cancer which lies outside mainstream thinking. Glenda's last diagnosis at the age of 74 has drawn attention to how attitudes towards the disease can still cause distress many years

later just when you think you have put it all behind you. For example, Glenda reported the difficulty she experienced in getting holiday insurance:

> The way she was interviewing me brought everything back. I just wanted to forget and say it's all behind me, it's in the past and I want to move on and do things   (Glenda).

Some women are given 'the all clear' from their consultant which generally means they are free of breast cancer at the present time but there is always the possibility of the disease returning and therefore they are labelled a risk in terms of employment and insurance purposes.

Stewart et al (2001, p.259) reported

> …a substantial minority of women perceived that cancer had substantially affected their personal and work lives. Although most felt their illness confidentiality was well protected and they disclosed freely to family, friends, and work, over 40% of women   survivors reported that cancer had affected their work in various ways, and nearly 20% identified insurance problems. It appears that disclosure sometimes results in negative work and insurance experiences.

The last of the three respondents who remain unemployed due to ill-health is Ruth who developed the disease at age fifty. She had been a full-time librarian but developed Electromagnetic sensitivity (EMS) when Wi-Fi was introduced in her workplace and at home. For years she had been struggling with environmental health in isolation but as soon as she was diagnosed with breast cancer the attitude towards her changed and she had the support of a medical team. She had already lost her job through her previous health problem (EMS) but managed to get voluntary work. Ruth tried to do the odd session whilst she was going through treatment for breast cancer because she said:

> It [work] kept that normality going although I was very ill and the confidence thing came later. But your body has to do a lot of mending. There is piles of research on electromagnetic problems but as soon as you mention it to someone for the first time, it turns heads. I worked hard researching it plus there was the chemo as well to understand (Ruth).

Ruth suffered from sleep deprivation from the electro pollution as well as the effects of the chemotherapy which left her too exhausted to do anything at all, let alone voluntary work. Ruth now works from home as a writer and poet and is always aware that she needs to protect her body from passing microwaves when she goes out of her home.

> I try to create a few positive memories from that really dark year…speaking as a poet now, I feel a bit like a dolphin just coming out of the water for a moment and then going back into this dark sea…I can say that there were some luminous moments during that dark year…it is not related to work but nevertheless… (Ruth).

Lindbohm et al (2013, p.639) reported that some women who retired early after their breast cancer had lower physical and mental quality of life than employed survivors. They experienced fatigue and anxiety more often than employed survivors. Damkjær et al (2011, p.274) cite The World Health Organization who state that work is an "essential ingredient of life satisfaction, health and well-being" and found that a substantial number of women either reduce their hours or stop working after breast cancer for various reasons.

Five of my respondents did return to their original full-time jobs, some of whom reported difficulties in returning. An important point was made by Louisa; a telecommunications manager, diagnosed at thirty nine who returned to her full time job but stressed it is important for women to give themselves time to recover from the emotional stress of breast cancer. She says you need to "cut yourself some slack" and don't be too hard on yourself when you are not where you think you should be:

> When you look around and see women running marathons and being super heroes it's not how you are feeling. You might get to that point eventually – well I have, but there is no time limit on it (Louisa).

Louisa makes a poignant point here that women who survive cancer need time to recover which, for different people, could be years or months after diagnosis. Thewes et al (2004, p.177) cites Dow (1991) who suggests:

Traditionally, the biomedical definition of cancer survival refers to the population of cancer patients who live disease-free for at least 5 years after treatment. In contrast, psychosocial definitions of survival view cancer survival as a process which begins with diagnosis.

Thewes' study adopts a psychosocial definition of the term 'survivor' and focuses on women from six to twenty-four month's post treatment who are in what they term as the extended survival phase and building on Mullan's (1985) three stage survival model whereby patients are expected to pass through different phases. The first phase is seen as the acute phase and begins with the diagnosis. The focus here is for the patient to "survive the aggressive treatment and deal with the overwhelming emotions engendered by facing potential death" (Thewes, 2004, p.177). At the end of the treatment when the patient is considered in remission she can encounter fears of recurrence until the next stage where the patient enters the permanent survival phase where the likelihood of recurrence is minimal.

My analysis of the informants narratives suggests that there is a problem with working with such a clinically defined survival model. Firstly, are women expected to pass through the phases in the same logical process and within a certain time frame? As Louisa states above, 'there is no time limit' on how women survive cancer and the lack of understanding of how the disease affects patients mentally is, according to Louisa, 'under-estimated' and should be on every HR agenda. I agree with Dow that the process may start from diagnosis but breast cancer can impact the lives of women for many years after diagnosis and treatment as some of my case-studies demonstrate. Secondly, how does this model accommodate the unfair treatment of long-term sickness or premature retirement due to redundancy as a result of breast cancer? Thirdly, many studies have shown that returning to work helps women recover from their breast cancer ordeal and is viewed by some as a way of getting back to 'normal'. Sometimes this means that they return to work during treatment and consider it a way of putting everything behind them as soon as they possibly can. But does this mean they have reached the last phase already and does the workplace provide the

kinds of support that are necessary for women returning to work after breast cancer. I discuss this in the next chapter.

6.5 Conclusion

There are many reasons why women return or don't return to work. For example, the above cases have shown that some women are under financial pressure to return, some are financially independent, and others rely on their partner's financial support. Whilst some women struggle to retain their jobs, others change career paths. Unfortunately, some women take early retirement or continue to be unemployed due to continuing ill-health long after the event.   Most women consider RTW as a coping mechanism that allows them to get on with life again despite the barriers that they have to overcome on their return. In the next chapter I follow five women's stories as they enter the return to work process in their various organizations.

Chapter 7

Managing the RTW of Employees with Cancer

7.1 Introduction

The first section of this chapter explores cultures and work practices in a group of organizations who are major employers in the South West of England. It is about managers' official discourses and the ways in which they narrate how they respond to the policy environment. It explores relationships between the state, private health, charities and employers around managing employee health and how this impacts women returning to work after breast cancer. The aim is to "make visible the ways the institutional order creates the conditions of individual experiences" (Smith, 2006, p. 109). For example, to understand how women navigate the ruling relations of organizations when they return to work after breast cancer, we must also understand the 'institutional order' that determines or limits the terms within which return to work occurs? Do employers provide workplace policies and practices that support or constrain their return? Secondly, I draw on interview data from five of my sixteen respondents who did return to work after breast cancer. This data illuminates the institutional field within which these five women are regulated and controlled and how they respond to its ruling relations. This data will highlight any differences between forms of knowledge reported by organizations and those women who are working with breast cancer. Supporting evidence is drawn from analysis of studies, reports and current cancer charity blogs hosted by Macmillan and Breast Cancer Care which provide useful supporting information about the problems women face on RTW after cancer.

7.2 Organizations' Workplace Practices on RTW After Cancer

I start by examining organizational practices used to manage RTW after cancer. How organizations draw on various frameworks, results in different approaches

and practices to how the RTW process is managed. For example, some draw on dignity at work policies, some approach the return through occupational health and wellbeing supported by employee engagement programmes. All have a clear set of statements around diversity and equality mobilizing the language of 'reasonable adjustments' and claiming they manage the RTW successfully by drawing on these frameworks. Gaps in these procedures and how employers take responsibility in relation to disability and workplace wellbeing, will be explored in the following section.

7.2.1 Dignity at Work

Organization A, a government sector employer, offered a case study illustrating how a woman with breast cancer was supported on her return through the organization's dignity at work policy. For example, throughout the period from diagnosis and treatment to return, there were three different occupational health referrals at different stages to ensure the "right support was given to the individual and the right preparations were made for her return to work". This provided accurate management information which the HR director said "allowed us to plan the individual's return and support her during her absence". The information was shared with line managers with the "full knowledge of the individual" (Organization A). This is backed up by a dedicated HR advisor who offers line managers policy and practical help. With three people involved in the individual's return to work process, they discussed what a phased return would look like, highlighting areas of stress within her work and carrying out a risk assessment to identify areas that needed adjustment or workshare. For example,

> There were changes to her tasking with some of the tasking shared out across the team. So the whole team work in a bit of a different way now because of looking at that (Organization A).

All staff participate in diversity and equality training, when inducted and then refreshed every three years. There are clear pathways regarding sickness absence and rehabilitation processes to support staff. The practices outlined by

this manager support the idea that being closely in touch and operating in-house, the individual is getting the right support she needs to make a successful return to work. During her early return, meetings with her line manager were weekly then reduced to every other week which offered a high level of support. They worked on a gradual increase to her full role "looking at the tasks and duties she performed". She was funded to do a mindfulness course on the hospital's recommendations and occupational health have reported "an excellent outcome in her return to work" (Organization A). This HR Director was asked to reflect on a single case in terms of the satisfactory implementation of equality and diversity policy to establish what can be learned from this – whether she thought that changes needed to be made or to develop their organization's policy further. Organization A offered clear pathways for return which I summarize here:

- It's about having a dialogue but never forgetting individual choice
- Making contact and keeping dialogue going
- Listening
- Removing barriers

Organization B, a local council, was similar to organization A in that they have a clear framework in place to ensure people are treated fairly. The first she described as their 'dignity at work' policy which sets out the organizational stance in relation to fair treatment. Additionally, two further policies are in place: a sickness absence policy and an occupational health policy which are underpinned by an employee assistance programme that provides advice on employment rights, counselling and other useful information. A case study was provided as an example of how an individual with breast cancer was managed on her return to work.

> She returned to work on a very limited basis for quite some considerable time to allow for the healing because she was still undergoing treatment and finding the impact of the treatment very tiring and fatiguing. She was unable to lift anything (Organization B).

The phased-return process allowed this woman to return to work but not necessarily on her normal contractual hours but she was paid for them for a

period of 6 to 8 weeks with an understanding that her phased-return should not exceed beyond this. If it goes beyond this period, which is what happened in the above case, then an adjustment to salary to reflect the change in hours has to be made or they can use a combination of their annual leave and flexi time to supplement this so their salary would not be diminished. In the individual case above, she was back working her full hours within 12 weeks. Whenever she needed time off for hospital appointments, her work was covered and her time off paid.

When asked to reflect on whether this case could be considered satisfactory, it was stated:

> I think if you asked the lady herself she would say that it was more than satisfactory…I think she felt that the organization had been very fair to her and more than supportive (Organization B).

The main points of a successful return to work were summarized as:

- Both parties need to engage in the process
- Make known access to all the forums of support available
- Respect individual choice

Because of the nature of this organization's mainly female clerical staff they seem to have experience, historically and practically of women's health, and issues related to breast cancer in the workplace. The management of workers with cancer comes under their 'Dignity at work' policy which is closely modelled on the General Medical Council's 2015 recommendations that individuals in organizations should take responsibility to ensure that everyone should be treated with dignity and respect, no person should be bullied or harassed, or victimized for making complaints of discrimination. If you are a manager the General Medical Council (GMC) states "you must take action if you are aware of bullying, harassment or victimization" (p.2). The policy sets out clearly what constitutes bullying. For example: criticism of work performance, deliberate isolation by ignoring or excluding a person, withholding information or removing

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areas of responsibility without justification, blocking leave or training requests without reason, deliberately setting objectives with impossible deadlines (p.3) all of which could act as barriers to women returning after breast cancer. Ahead of the 2015 general election, Macmillan called for every person diagnosed with cancer to be treated with dignity and respect throughout their cancer journey. [38] By placing breast cancer patients under their dignity at work policy, Organizations A and B have structures in place to ensure that cancer patients are treated fairly and with respect.

7.2.2 Occupational Health

Organization C, a large food retailer, similar to the above organizations, did not separate out breast cancer specifically under their diversity policy but stressed that within their occupational health framework if someone is ill and needs to have time off for treatment away from work and then returned, there are very clear guidelines about how this should be managed:

> People are supported through their treatment and appointments. If an individual needs to work from home, work from a local store or they cannot work on a check-out because of restricted mobility, our return to work programme allows people to come back on light duties, reduced hours then over a period of 12 weeks we will get them back to their core hours and core job. Where they cannot do their core job – we are a business of scale and diversity, we will find a different job for them. Our aim is to return them in the business rather than for them to go (Organization C).

The case study they offered, charted the return to work of an individual with breast cancer who was supported until she had to finish working for the company because her cancer became terminal.

> The employee went for treatment, booked it out in the diary and two hours later she would be back in the office. When she knew she would be having more invasive treatment she would book a couple of weeks off. Some people are ill from day one and they can't be at work (Organization C).

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[38] Macmillan *Putting the dignity and respect of patients first: the general election 2015*

Another example was given of how colleagues fundraised or supported people going through cancer.

> One lady lost all her hair after treatment, all of her team just shaved their heads and we all wore scarves in support (Organization C).

7.2.3 Language of Equality and Diversity

Every person with cancer is protected by law from discrimination under the Equality Act 2010 and the Disability Discrimination Act 1995 (DDA). The Equality Act combined previous acts in one piece of legislation in England, Scotland and Wales and in Northern Ireland, the DDA has been extended by Disability Discrimination Order 2006. Within these acts employers cannot treat a person with cancer less favourably than others or discriminate against them because of their disability – this applies also to cancer that is in remission. Employers are required to remove any barriers in the workplace which substantially disadvantage employees with cancer compared to others who do not have cancer. The act also protects employees from harassment and victimization at work.

Each organization had an equality scheme in place which states that they should not discriminate against people with disabilities. They have the documents to show that this is in place. They produce these because they are legally required to do so. When asked to talk about their Equality and Diversity policies in their workplace each offered a very generic picture of how they interpreted disability legislation and in some cases this seems to be very process driven and there was no evidence to suggest that the thinking went beyond the process that leads to compliance requirements. Smith states:

> Institutional work processes are organized by conceptual schemes and distinctive categories. These are the terms in which the accountability of the work is produced, and procedures of accountability provide one of the main ways that various local settings are pulled into translocal relations. (Smith, 2006, p.37)

Professionals are trained in these procedures using institutional language which can be "empty" and conceal a lot about the practices. Interviews can result in producing "little usable data beyond the expression of institutional ideology in action" (ibid). But understanding what the organizational ideology is and how it impinges on the RTW process is relevant not just to this research project but also to future research projects on working with cancer. Citing Bakhtin (1981) Smith (1999, p. 136) suggests that words become "one's own only when the speaker populates it with his own intention, his own accent, when he appropriates the word, adapting it to his own semantic and expressive intention". For example, managers in organizations receive other people's words which have been given meaning elsewhere. The managers involved in this research project have been handed down legislation (The Equality Act 2010) by the State but these rulings must enter into dialogue before they can make it their own i.e. written into the ideology of the organizational practices.

It is not an uncommon finding in many organizations as Smith (2006) suggests to find policy that is "empty" of meaning especially if there is nothing that is driving meaning forward. There is no 'push' from government for employers to think about it in a more complicated way. Therefore, a lot depends on whether a manager takes responsibility to bring legislation into dialogue at their local level so that it can be reworked, possibly through the actual experiences of employees with breast cancer in the workplace who may enhance understanding of how this disabling disease impacts their working lives, beyond the level of generality.

Where there is a lack of meaningful engagement with issues around disability at work, my data seems to suggest that there is a lack of personal experience to drive awareness forward. For example, three out of the five organizations I interviewed could illustrate how they put policy into practice because they had had personal experience of an employee returning to work after breast cancer. This may mean that a person's experience possibly drives policy in a meaningful and proactive way rather than a compliant reactive way where meaningless language is used. Following Bourdieu, Web et al (2002, p. 95) state language is

used in the battle to seek legitimation of ideas. Language becomes a powerful weapon in the battle because it is "both a 'structuring structure' (it provides the means for understanding the world) and a 'structured structure' (it is the medium by which these undertakings are communicated". Language can bring things into being by naming them and they become accepted as legitimate. Bourdieu suggests we unconsciously accept taken-for-granted ideas which he refers to as 'doxic' power. The 'objectively real truth' which is defended in orthodoxy, and attacked in heterodoxy, Bourdieu believes, is used to explain how "subjects adjust themselves to ideology's rules" (Web et al (2002, p.96).

Bourdieu states:

> Private experiences undergo nothing less than a change of state when they recognize themselves in the public objectivity of an already constituted discourse…any language that can command attention is an 'authorized language', invested with the authority of a group, the things it designates are not simply expressed but also authorized and legitimated (Bourdieu, 1977, p.170).

In organization B above we have seen how the discourse attaches authority to the experience when the experience can be made to fit within the discourse i.e. within their dignity at work policy. Once the experiences become talked about and written in text they become authorized. These case studies create meaning in their 'dignity at work' policy.

> they don't exist in a dry dusty cupboard in HR… from when an individual joins the organization…they are out there in terms of staff awareness (Organization B).

Similarly, Organization C, outlined how they actively encourage inclusivity and diversity at all levels throughout their business. They have a diversity council with networks for all key areas such as Asian, Afro-British Black-Caribbean women, disability and have the biggest Lesbian/Gay/Bi-sexual/Transsexual (LGBT) network in the UK. They publicly report on equality of pay. Their difference between male and female pay is less than 1% which they state is statistically insignificant. Diversity is intrinsic to the way they work.

> The policies come to life rather than just being written on a piece of paper. Throughout all our talent cycles we take a lens, whether it is our promotions, our aim is always to have diversity on every short list whether that is non-British or whether that is female or age or whatever (Organization C).

This HR Director feels that there is a need to personalize the policy and that every case is individual. Flexibility and patience are needed in order to provide support to that individual. She feels that "some people just pick up the policy and that's it, run it by the person…like a sausage machine". She feels that in order to interpret intent, people's values should be used to "apply the policy that is right for the individual" (ibid).

Organization D, an energy supplier, advised that last year breast cancer awareness was driven through the women's network:

> The presentations that were given last year were filmed and are now under my cancer tools and are more accessible when linked to them. (Organization D).

In a sense the language used in organizations is, as Bakhtin (1981) cited in Smith (2006, p.118) describes, "half someone else's" which in this case, relates to what must be spoken about disability legislation etc., originally handed down from government ministers to be set out in policy. "These are conceptual systems, forms of knowledge that carry institutional purpose and reflect a standpoint within relations of ruling" (ibid) but which can be meaningless if they are not related to personal experience as witnessed above or as the next section discusses, there should be a common approach or shared understanding of wellbeing if this is used as a framework for disability.

7.2.4 How Breast Cancer Fits into Differing Approaches to Wellbeing

This section explores how wellbeing has evolved in workplace cultures, how it is used in different ways in the management of sickness absence within

organizations, and how this impacts women with breast cancer. Firstly, I outline some approaches and the difficulties in measuring wellbeing. Secondly, I explore some responses offered by my respondents and lastly, evidence from reports gathered in this research.

In 2010 David Cameron launched a programme in line with initiatives of OECD and EU levels of "measuring national well-being: *Measuring What Matters* and commissioned the UK Office of National Statistics (ONS) to develop new indicators for well-being that went beyond economic growth in measuring the quality of life. Cameron's intention was to:

> ...start measuring our progress as a country, not just by how our economy is growing, but by how our lives are improving; not just by our standard of living, but by our quality of life. (Cameron, 2010).

This, he stated, would lead to government policy focusing on the things that "make life worthwhile" (ibid). There would be a shift from monitoring opinions of society as a collective whole to measuring individual wellbeing (Tomlinson and Kelly, 2013). However, there are problems with using different frameworks in the measurement of individual wellbeing because of the three main approaches; 'Objective', 'Subjective' and 'Capability'. The objective account defines wellbeing as a person's way of living not particularly a psychological state. It looks at available resources and opportunities. However, these factors can change over time and resourced-based accounts of wellbeing can be challenged because of discrimination which may prevent a person transforming their capital into life choices as in Laura's case. Despite her capital as a GP she was refused entry back to work after a long absence and was told she was too old to retrain.

Those who argue in favour of the new subjective wellbeing approach say that it is more democratic and respects what people believe is important in their lives (Diener et al, 2009). However, people adapt to external circumstances, particularly the poor and disadvantaged who suffer hardship, can still remain

positive (Sen, 1985). Breast cancer survivors are encouraged to remain positive and may report good or bad psychological wellbeing depending on the type of support they receive on the RTW. Both subjective and objective approaches to wellbeing are therefore problematic for women who want to RTW after breast cancer. If we apply Sen's capability approach then breast cancer returners should have the right to RTW "without prejudice or harm and to have the capability to flourish and lead a worthwhile life" (Sen, 1999). However, reflecting on Sen's capability approach Clark (2005, p.1339) reported the results of a study which suggest:

> the capability approach overlaps with both utility (happiness, pleasure, etc.) and resource-based concepts of well-being. The distinctions between commodities (and their characteristics), human functioning and utility is less robust than Sen implies. In particular, the capability approach needs to make more space for the role of utility (defined broadly to include all valuable mental states) and say more about the material basis of well-being.

Edwards and Imrie (2008, p.337) argue the wellbeing agenda in its present form, is "unlikely to contribute to the development of social, theoretical, or more politically progressive, analysis and understanding of disablement in society". Citing Moloney (2006, p.27) the authors state that commanding us to be happy is a form of social control and promotes blame culture. This "politics of happiness" seeks to "eradicate negative emotions through interventions" (Edwards and Imrie (2008, p.338) but ignores vulnerable groups of people, particularly those with disabilities or those who lack cultural capital (Genisi, (2016) who do not meet the wellbeing ideal. There is a tendency to "redefine public issues as the private problem of the individual" (Furedi, 2004, cited in Edwards and Imrie, 2008, p.337). This is problematic for breast cancer patients' RTW where depression often occurs after diagnosis and treatment which can continue with them into work. Unhappiness created by mental illness is further enhanced by the lack of support from their employers who make no adjustments to their work practice because the managers are not trained to deal with emotional wellbeing. Responses from my respondents show differences in attitude to Health and

Wellbeing. Judith states that her organization is promoting links to private health care and wellbeing. She remains skeptical about wellbeing and sees it as:

> just a sticking plaster. Every year our management push us to do more. There are more people under stress and there is less and less tolerance of any kind, particularly mental illness. I have nothing against wellbeing, it's a great idea. I think there is something ironic about saying to people whose lives are being made more difficult all the time, why aren't you more well? (Judith).

Job loss after breast cancer which is a social issue, is transposed into a psychological issue for some women where there exists a culture of blame. Edwards and Imrie (2008, p. 342) cite Bauman (2002) who states that the well-being agenda leads to a view that if an individual falls ill, "it is because they were not resolute or industrious in following a health regime. If they stay unemployed, it is because they failed to learn the skills of winning an interview or because they did not try hard enough. The authors suggest there is a danger that "wellbeing politics and its accompanying evidence base, which arguably leads to the invention of new categories or problematisations that give government a mandate to 'act' – may be less about individual autonomy and more about exercising subtle forms of social control" (Edwards and Imrie, 2008, p.343) to make those groups who do not fit the ideal of the wellbeing criteria or who are not actively engaged, to become more responsible or just to 'try harder'. This may be an impossible task for women suffering from the effects of chemotherapy who may be willing but not able to carry out their jobs.

The act of taking self-responsibility to realize one's potential is part of a governance which "focuses narrowly around utilitarian objectives relating to the re-shaping of welfare, and connecting notions of personal wellbeing to active participation in the labour market" (Edwards and Imrie, 2008, p.344). It is part of the government's programme of getting people off benefits and back to work - from welfare to workfare. Wellbeing is the connecting bridge "between the (responsible) self and other forms of sociability" as in the recent push to get disabled people working and off benefit. But due to the reductive description of

disability and wellbeing, the missing link in the lives of disabled people is the "material disadvantage and structured inequalities" (Edwards and Imrie, 2008, p.346). The authors cite Donovan and Halpern (2002) who argue "income is far less important than material status, unemployment status and health" although disability researchers such as Barnes (1991) and Oliver, (1990) say that it is not necessarily the case. The issues may involve health and/or impairment and (un) employment status and wider "situational contexts, so to separate one off from another...is problematic and not likely to lead to useful or appropriate analysis of the interrelationships between disability and wellbeing (ibid).

Atkinson (2013, p.1) uses a social sciences approach of situating wellbeing dependent on "the mobilisation of resources" so that policy interventions can address "relationalities of particular social and special contexts. She says, "the word is everywhere" as in individual action (Rath and Hartner 2010), marketing (Kim and Cho 2012, Little, 2012), employer criteria (Robertson and Cooper 2011) and government intervention (Stiglitz et al 2009). Therefore, it is important for academics to reflect on meanings of wellbeing particularly by government policy makers which she suggests, "foster a critical engagement with the current enthusiasm for wellbeing" because it is a complex and multidimensional concept with different ways of defining and interpreting for policy purposes (Atkinson (2013, p.1). Furthermore, she adds, "Policy-facing research on wellbeing can be seen as most often embedded within an unchallenged line of argument" (Atkinson (2013, p..2). Atkinson stresses there is a need to standardize (use the same) indicators and monitoring, (across approaches). She advocates we should look beyond economic measures of social progress and not just see it within existing discourses located in current policy, which mostly deal with the abstract nature of wellbeing in which government has a tendency to conflate wellbeing with health when in fact it has wider political concerns related to development goals.

The abstract nature of wellbeing was referred to by Organization D when I asked for clarification of their wellbeing agenda:

It has been around for a while. It is one of those words that is like sustainability, it doesn't mean anything to everybody. We had a wellbeing forum about four or five years ago and to be perfectly honest it just didn't survive (Organization D).

If wellbeing "constitutes some kind of commodity, an entity that can be acquired, or at least achieved" as Atkinson (2013, p.3) suggests and particularly if it incorporates the notion of 'resilience' then this could have ramifications for women's RTW after breast cancer whereby they are caught up in performance related work goals with a personal responsibility to achieve these.

Early positive psychology movements attributed personal action to managing health conditions and behaviours which was labelled as a self-directed approach to wellbeing. This leads to policy responses that focus on "individual deficits in fostering and sustaining positive wellbeing" (Atkinson 2013, p.5) which produces an even more dominant position in wellbeing literature where we are told we can achieve these things. But Atkinson highlights counter claims by some authors to reject the power of subjective wellbeing in illness such as cancer (Coyne and Tennen, 2010; Ehrenreich 2009) and research grounded in critical social and cultural theory where researchers challenge the self-management or failure to achieve wellbeing by individual citizens, particularly positioned through Foucauldian analysis (ibid). Is wellbeing and resilience part of outcomes to be achieved or "rather the processes through which our conduct is directed according to the requirements of the political or economic imperatives of others" (Ibid). Whatever position we take – outcomes or process, wellbeing according to Atkinson (2013) "needs to be understood not as sets of entities to be acquired as internalized qualities of individuals but instead, citing Kesby, "as a set of effects produced in specific times and places (Kesby, 2007 in Aitkinson, 2013, p.4). It is both situated and relational and framing it in this way "makes explicit that wellbeing can have no form, expression or enhancement without attention to the special dynamics of such effects" moving away from centering on individual acquisition (Aitkinson, 2013, p. 8).

There is evidence to show that some organizations focus more on wellbeing in order to prevent sickness absence. For example, Organization C has a strong emphasis on health and wellbeing. There is a company GP on site and gyms in their main offices. Throughout the field in every store, staff are supported by a personnel manager and HR manager.

> when someone is ill it is a key part of their job to support that individual alongside the occupational health adviser to do what is best for that individual based on their work but also on their illness (Organization C).

To "do what is best" for the individual might not always be the case in all workplace practices as the CIPD, the dominant voice of the HR 'profession' report outlines below. In a policy report, *Growing the health and well-being agenda: from first steps to full potential* (2016, p.2) the CIPD states:

> Wellbeing is more than an avoidance of becoming physically sick. It represents a broader bio-psycho-social construct that includes physical, mental and social health…Positive wellbeing can also benefit the local community and, more broadly, the country as a whole because of well people requiring less support from the health services.

CIPD believe line managers, particularly HR managers, play a pivotal role in shaping work experiences and 'bringing people management policies to life' but they do not always have the appropriate training particularly in stress management (ibid). Historically wellbeing covered a narrow field of health and safety and reducing work injuries but has steadily broadened out to include more government led practices. Inextricably linked to wellbeing is employee engagement - which may take on different meanings in different organizations, where employers ensure 'work culture, leadership and people management are the bedrock on which to build a fully integrated wellbeing approach' (CIPD, 2016, p.14) that is not seen as 'add-ons' only to be abandoned when budgets are cut. An example of how this is embedded into workplace culture is shown in Organization D below.

There are two main aspects to consider in sickness absence. Firstly, there is the cost through loss of productivity which is what employers seem to focus on. Secondly, there is the moral aspect of presenteeism which is defined by people

returning to work when they are unwell. Department managers examine productivity in relation to short or long-term goals and are forced to make savings within their departments depending on the profit/loss of their companies. Staff absence is a major factor in this evaluation. In an independent review of sickness absence Black and Frost (2011, p.93) estimate the "cost to the economy of sickness absence is estimated at around £15 billion" which includes sickness absence management and healthcare costs – less quantifiable costs such as quality of life or wellbeing are not included in this figure. On the employers' part there is payment of wages for no output therefore it is an important aspect impacting productivity goals. Depending on the size of the organization there are several ways in which firms deal with sickness absence. Young and Bhaumik (2011) cited in Black and Frost (2011) found larger firms were more likely to offer access to occupational health services or subsidized private medical insurance than smaller firms. Also, higher paid professionals were offered insurance 'against loss of income' (Black and Frost, 2011, p.110). Whatever framework employers use to view wellbeing, sickness absence almost certainly comes down to an economic variable as Black and Frost report above.

Within their management policy Organization B looks at sickness absence both short and long term and plans for adjustment are made accordingly. However, for health care advice, this service is out-sourced to a private company which provides:

> case management advice in terms of the impact of the illness, the level of progression, the likely potential of the individual to return to work, whether or not any advice may be given with regards to short-term adjustments or even longer-term adjustments (Organization B).

There is an employee assistance programme which provides staff with access to a help-line offering advice about employment rights, access to counselling and all other information that they may need "whilst they are making their journey" back to work.

Up until recently, organization D has employed a resident medical officer who they say was forward thinking although clinically driven rather than socially driven:

> The clinical side has a chunk of wellbeing but the more we get into this the more we realize it is a wider set of things, the engagement angle for instance (Organization D).

Despite having their own in-house occupational health with physiotherapists this organization could not offer information on a particular breast cancer case study. This may mean that they weren't aware of any cases or they simply did not have anyone with breast cancer. They do however, show evidence of focusing on workers' health by putting strategies in place that create signposting for mental fitness, physical fitness and any future work which can be laid on top of their foundations for occupational health. This is managed by a strong wellbeing leadership team. The organization investigates the reasons for sickness absence and questions how people are managed in this process:

> We have had a real burst in absence this year but actually you know we are very heavily prone to be processed. You can do far more damage in chasing a figure to get people at work when actually you shouldn't. And so next year what we will do is to roll out a particular look at breast cancer (Organization D).

By processed, I believe the meaning given above refers to the loss of productivity as a result of sickness absence but the moral issue of presenteeism - getting people back to work when 'you shouldn't' is not a good way to manage sickness absence and loss of productivity figures. Managers are governed by processes. Smith suggests that in the relations of ruling we are driven to act in certain ways and "Organizational and political processes are forms of action…ideologically structured…integral to the practice of power, to getting things done" Smith (1987, p.17). Atkinson (2013) suggests wellbeing can also be viewed as part of a process in which we work towards a desirable set of goals or criteria.

A TUC report on Work and Wellbeing (2013, p.12) found that a review of Employee Assistance Programmes (EAP) conducted in 2012 showed little evidence of this service making any difference "to either the wellbeing of the workers in general or to sickness absence or performance".

Wellbeing is a word that has been connected closely to health, so much so that at times government and employers lose sight of more serious health problems in the workplace. Being obsessed with diet and fitness takes the focus away from things like working with cancer. Wellbeing, like its partner mindfulness, has become a buzzword although 'it doesn't mean anything to everybody', it is now being promoted as a general health agenda managed by private consultancy firms who sell wellness programmes to employers as we have seen above. In *Work and Wellbeing: a trade union resource* (2013, p.2) the TUC warns that management sometimes uses the phrase as a way of by-passing union involvement and describes its overuse:

> Well-being has become one of the most over-used phrases in the English language. It helps sell anything from yogurt to holidays, pillows to pills. For some people the phrase refers to levels of happiness, while others think of it as a healthy body and mind. The government has even started a well-being index intended to gauge the quality of life of people in the UK, as well as environmental and sustainability issues and even the country's economic performance (ibid).

The above report stresses the importance of what the TUC calls 'prevention first' which is what they mean by primary prevention - a strategy for workplace health and gives advice to reps on how to tackle management when "work and work practices are likely to be the cause of workforce ill-health" (ibid). Furthermore, the report suggests that most well-being issues are relating to how work is managed and if there is work overload, this may be the cause of stress as Judith and others have found. This is clearly a health and safety issue related to prevention. The report goes on to say that "If an employer wants to improve the health of the workforce then they should address the issue of illness and injury caused by work first, as that is what they have most control over" (p.5) In the case of women returning to work after breast cancer, if there are no back to work

plans in place or adjustments made, then this lack of prevention by the employer, can lead to illness such as stress which could have been avoided in the first place.

CIPD (2016) argue that wellbeing at work should include plans to limit harm and that "requires organizations to actively assist people to maximize their physical and mental health". They see HR Directors as gatekeepers in initiating wellbeing strategies. Unfortunately, many employers concentrate on changing the behaviour of the workforce, i.e. stopping smoking and getting fit, rather than looking at the workplace practices and the work environment. The situation for cancer patients will not improve until there are measures in place to facilitate their return. Managers should be trained to support or refer employees on to the rehabilitation services when needed. Health and wellbeing is established around good employment relations, which are built on effective policies in the management of staff who feel valued. For example, for Tracey there was the lack of understanding and concern for what cancer patients go through. Her line manager made no attempt to try to understand that she was feeling fatigued and vulnerable. This was brushed off and Tracey failed to get this message across:

> It is the employer's responsibility to be there…even an educated, very helpful employer did say to me 'well I get tired at the end of the day too'…Even the best have those thoughts (Tracey).

The above comment shows that Tracey's line manager is minimalizing the fact that Tracey is feeling fatigued by saying that she gets tired also.

7.2.5 The Role of Private Health in Supporting Cancer Patients Back to Work

Although we cannot determine whether outsourcing health care services to a private company is a factor for non-engagement of disability issues which could lead to the distancing of problems involved with working with cancer, it seems

reasonable to suggest that managers could be denied the opportunity to be able to share in the experiences of individuals who return to work after cancer. Furthermore, they might not be able to use a particular breast cancer case study as a meaningful way of driving forward issues around disability and encourage dialogue within their organization as some of the above case studies demonstrate.

Two private health care companies are used by Organization E, one deals with occupational health management and the other is their employee engagement services which handle information about counselling, financial matters and claims etc. Each of the two websites offer information which can be used by employers, employees and GPs. But because of the generic nature of the information it seems doubtful that GPs would gain anything from this on-line service. Similarly, it is not useful either for employees, especially women with breast cancer as their brief references to cancer are not breast cancer specific. Furthermore, there are no case studies of this type of cancer on their website. Unions remain wary about the lack of impartiality when work-related problems from employees are discussed[39]. However, from a business point of view in terms of productivity the web sites offer a range of useful information about absenteeism or presenteeism – a term defined as the 'act of attending work whilst unwell' which is most relevant to my research. However, there are few studies which document breast cancer patients not feeling fit to return they mostly show how presenteeism is a response to interventions addressing absenteeism.

Organization D suggested that there are wider issues to consider when focusing on ill-health which impacts on others, partners, mothers, and their children. Doyal cited in Wilkinson and Kitzinger (1994, p.80) also identifies these wider issues and suggests,

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[39] *Work and Wellbeing: a trade union resource* (2013) p12 The TUC.

the boundaries of work and home are more permeable for women than for men and their mental and physical health will be moulded by their experiences as waged workers, parents and partners.

One example of how Organization D addresses these wider issues is to assist employees through a programme that offers help to families:

> In our world the occupational health and wellbeing is drawn together but with private medical insurance to get the benefits. What we are looking at is can we make a direct link from one service to another. The treatment between the private areas compared with NHS, does financially offer the chance for partners to go and stay near where the cancer centre is, so that would mean they (employer) would pick up the hotel bill but the treatment in the private area is no different to what it would be in the mainstream NHS (Organization D).

So far, I have looked at the institutional relations of organizations which have raised particular issues highlighting the return to work processes within five major employers. The type of employer intervention mentioned above is limited to a core group of workers - not those on the periphery such as temporary staff, agency workers and contractors. These groups are excluded from even the limited support offered by employers which is evident in some of my respondent's narratives. I now turn my focus to how women returning to work after breast cancer have responded to their own organizational culture and practices.

7.3 Women's Experiences of Workplace Practices on their RTW

In this section I explore the workplace practices which impact breast cancer informants' RTW and how they respond to this. Examining the return to work process is paramount in highlighting the problematic for women who want to continue working after their breast cancer diagnosis and treatment. Few RTW studies have focused on work-related factors such as work adjustment and social support and how employees are accommodated on their return: whether they need reduced working hours or whether they can work from home if the travelling time to and from work is too strenuous. Nilsson et al (2013, p.2756) stresses the

importance of this and found that "Lack of such adjustments may increase the risk of sickness absence whereas access to adjustments increases the likelihood of RTW when having some work capacity". The narratives recorded from my own research go some way in understanding the principal findings of Cathy et al (2002) that the probability of breast cancer survivors working is 10% less than for women without breast cancer. Only five out of sixteen respondents I interviewed, returned to their original jobs, one retrained in another branch of general practice, but most experienced some problems settling back into their jobs. Their narratives below provide a window on how the ruling relations of their organizations affected their RTW and their responses.

7.3.1 Work Adjustments

Pauline, a Medicines Management Technician, aged 58 had to fight for work adjustments to be made on her return. For example, she reported not being able to cope with the pain in her back because of her breast reconstruction and found it painful to carry a laptop between different work stations. Using a laptop was an essential part of her job so she requested a carrier on wheels in order to support her disability. Pauline was not very vocal and the last thing she wanted was to lose her job so she felt she could not push her employer too hard for the adjustments she needed.

During diagnosis and treatment Pauline stressed that all decisions are made for you and you feel a loss of control and not coping. But when you finish treatment you are suddenly out there on your own and faced with returning to work. She believes employers are not aware of the emotional trauma of receiving a cancer diagnosis and treatment regimes that women face and there is little support to help them adjust when they return to work. It is difficult for women sometimes to find the strength to fight for their rights even if they are protected by the law because initially they are feeling vulnerable and not in control as Pauline suggests.

Louisa, a telecommunications manager, aged 41, reported that a discussion took place about a work plan on her return. Her manager was new and not familiar with the procedure. Louisa was asked:

> Is there anything that is going to stop you from doing your job? To be honest at that point after the radio therapy, physically no, I didn't need any assistance physically. I was slightly weak in one arm but it didn't matter – I was only moving a mouse (Louisa).

Like Pauline, Louisa reported the lack of understanding from employers about the emotional impact of returning. She says people underestimate the magnitude of the emotional trauma and don't see it as a disability:

> It is not even on anyone's agenda. It is so huge, that it just knocks you off your axis …You don't get time off or leeway for that because you are physically okay (Louisa).

Organization C stated they do not separate out breast cancer from other illness because under their occupational framework they have clear guidelines about how people are managed when they are ill and need time off for treatment. Blinder et al (2012) stress the importance of employer cooperation in maintaining breast cancer survivorship "thereby allowing her to preserve her 'normal' work environment and benefit psychologically from the return to work experience" (Blinder et al 2012, p.768).

Tiedtke et al (2012, p.6) also refers to the psychological pressures affecting women working with breast cancer and found "fear of recurrence a particular cause for anxiety" and that they "felt powerless to manage their insecurity". Pauline and Louisa's cases both support these findings – Pauline reminds us that when women are feeling vulnerable and not in control, they do not have the strength to fight for their rights even if they are protected in law. Similarly, Louisa focuses on the magnitude of the emotional trauma which she says employers don't see as a disability. I would argue these case studies show that employers

have a responsibility to understand the specificities of different illnesses so that they can recognize the different needs of different disabilities in order to make reasonable adjustment and offer on-going support. Nilsson et al (2013, p.2757) state that to the best of their knowledge, their study "is the first study investigating the importance of social support at work and work adjustments for sickness absence early after breast cancer surgery". Different cancers or illnesses cannot be lumped under the same sickness absence process because each requires different assessment and different support. The support that Pauline and Louisa needed from their managers was an awareness of their specific emotional needs.

7.3.2 Emotional Stress

Despite the availability of a counselling service Louisa decided not to take this up because it was not cancer specific and she didn't think it would have been helpful. The way she coped was just pushing her problems to the back of her mind and getting on with things, "almost ignoring it". But six months after her return Louisa was still not coping. She reported feeling like a fraud as she was saying "I'm fine" when people asked her how she was:

> Deep down I wasn't telling them that I was drinking too much, I was totally depressed and stressed out at work. The biggest shock is under-estimating the emotional effects that it will have on your life. You need to cut yourself some slack when you are still struggling after two months, three months – you are not even to the point when you can reflect on it yet as you are too scared to look back. It is long-term, it's a big deal (Louisa).

In Louisa's mind, employers don't understand the enormity of this disease and how it affects your emotional as well as physical body. She states there is a need for employers to understand that cancer recovery is not quick for most women. As she stresses, just because you may look physically okay, the emotional impact that cancer has on your life is more difficult to come to terms with. The emotional stress of having breast cancer might possibly have been supported better if Louisa had accepted the offer of counselling although she states that she

had had some NHS counselling and found that "every time she came out feeling dreadful" and therefore adopted the attitude of just getting on with it. Louisa's experience is opposite to that of Organization A where, through their occupational health service, they were able to offer weekly meetings which resulted in a high level of support to their employees returning to work after breast cancer. Offering to fund her to do a mindfulness course, they reported, had excellent outcomes. For many women coping with a cancer diagnosis is a traumatic event which "can be related to declines in personal wellbeing and increases in distress" (Abdollahi and Khan, 2014, p.111). The authors point out that lack of social support can increase the risk of depression in cancer patients and "having to reframe their future may result in anxiety, depression, confusion and hopelessness" (Abdollahi and Khan, 2014, p.112). Their research was based on a psycho-education intervention programme that incorporated mindfulness, building on the work of Segal, Williams and Teasdale (2002, 2007). The authors found mindfulness-based therapeutic practices are now becoming used in a range of patient disorders and cite research by Shennan et al (2011) that shows "improved quality of life outcomes in breast cancer patients" (Abdollahi and Khan, 2014, p. 114).

Judith, a college lecturer and teacher manager aged 58, reported that even before she returned to work she received a stressful telephone call from the company out-sourced to manage the health of employees in her organization:

> they [private company] phoned me up at one point when I was coming to the end of my month and said if I didn't go back to work, my salary would be cut. I issued a formal complaint about that. They were actually quite wrong, I get six month's sick pay, not one month. They obviously confused me with a member of the admin staff. My complaint was upheld. They were appalling. I was so glad the college got rid of them after a year – they were dreadful (Judith).

The actions of this private health company added to Judith's emotional stress. The difference in capitals, discussed in the previous chapter, becomes apparent here in relation to work status. For example, Judith as a member of the teaching team has more capital than an admin worker. She is entitled to six month's sick

pay whereas admin workers get one month. This could result in women in lower status positions not having enough time to make a satisfactory recovery after breast cancer treatments before returning to work. For Judith, this could have been avoided if staff had been better trained and treated her with the dignity she deserved.

When Judith returned to work whilst having her treatment she requested the she didn't have a teaching timetable for one term. She would have liked a phased-return to teaching after that but was not offered it. She feels that this was due to a lack of imagination on her employer's part. However, she stated that they probably would have agreed this if she had pushed for it. She reports:

> I don't think my institution was unhelpful, I think like the hospital, they were muddled and busy thinking about something else. The college definitely did the right thing and my line manager agreed the right thing. There wasn't any emotional support. I don't honestly know whether I would have been very comfortable with that (Judith).

The back to work transition for Judith was made easier mostly because of the people she worked with at her college more than support from human resources. Overall, she describes being treated fairly:

> …they were pleasant enough [HR] but not very pro-active. I deal with them a lot because I am a Union case worker. If you have a reputation of being a pleasant, cheerful, hardworking person, you tend to get…particularly if you have something like cancer which is such a nice clear cut thing, you either have cancer or you haven't and it isn't your fault. You tend to get pretty good treatment but something like depression, people are not shown the same tolerance (Judith).

Although Judith was not offered any emotional support she states she wasn't sure whether she 'would have been very comfortable' talking to her manager about emotional support. In her experience she found that there was not the same tolerance for depression as there was for cancer.

Feeling uncomfortable talking to managers is problematic which could be as a result of their lack of awareness of the effects of breast cancer. The CIPD report (2016, p.5) suggest that as part of the five domains of well-being line managers should be able to "have difficult conversations" with staff in relation to mental health. Organization D focused on breast cancer awareness driven through their women's network thus inviting all managers to share experiences and access their 'cancer tools' if they are in a situation where they have to manage women with the disease.

The pattern of employers' lack of understanding continues with Tracey, a teaching assistant, aged 51 who reported that although she felt that she wasn't badly treated:

> There was quite an attitude of 'let's get on with it' and that's probably what I needed at the time. The other staff were lovely…they were all very supportive indeed. The biggest battles have been psychological and that is what I am still struggling with... getting back into work is really a good thing for that but I still feel very different, very vulnerable (Tracey).

Tiedtke et al (2012, p.683) refer to breast cancer patients feeling vulnerable in their study of women preparing to RTW. They suggest what is needed is "an understanding, supportive, and cordial work environment during and after breast cancer diagnosis and treatment can help and encourage survivors, facilitating their work resumption".

Tracey was still very emotionally affected by her breast cancer experience although she worked with a stoical attitude of getting on with her work. When she relayed this information during our interview she became quite tearful and I could see that this was very stressful for her to have her emotions still so close to the surface. Moreover, as an OT she recognizes how stress can affect cognitive ability:

I think definitely there is 'chemo' brain'…I am quite sure it exists. I always struggled a little bit with remembering names but I am worse now. There may be an element of stress override as well (Tracey).

Tracey reported trying to 'normalize' her life after breast cancer and saw the work place as the place where you will get back in a way. The one thing she did need from her employers was for them to understand that she was a bit more vulnerable but when she talked about the psychological effects, her manager just did not respond. Tracey insists:

We do need to be talking about this…it's like the poor relation (psychological symptoms) and they are not separate things. I was lucky to have a TA who was happy to step in to cover my workload. She stayed in the classroom with me and withdrew gradually so I did have a phased return in that sense (Tracey).

It appears from the cases above that although the women say they were not badly treated nevertheless, line managers appear to need more training about working with cancer and to be able to ask questions about how they can support the return whether it be phased or simply making adjustments to work ability. Employers need to offer a RTW programme that is flexible in terms of supporting the physical and mental health of employees which all of the above respondents reported a lack of.

In a briefing paper, *You Don't Look Disabled,* the TUC states, there are stereotypes of disability 'applying only to wheelchair users or blind people' and call for all managers and supervisors to participate in training. Psychological symptoms are missed or not taken into account because of lack of awareness. Added to this lack of awareness, rehabilitation services vary in access, as my data shows, due to organizations drawing on various frameworks to manage the RTW process. Mental health symptoms that are not visibly apparent such as emotional stress and depression have in fact been raised by others. For example, an NHS report by the Independent Cancer Taskforce proposes a strategy for delivering a series of health initiatives across patient pathways outlining what cancer patients can expect from the health service. The report

suggests that there are two main reasons that depressed cancer patients do not receive adequate treatment:

> First, the depression is often not detected. Second, effective treatment is not provided. Integrating depression care into cancer care can overcome these barriers to effective management and achieve 'parity of esteem' for patients' mental and physical needs (Independent Cancer Taskforce Achieving world-class cancer outcomes: a strategy for England 2015-2020 p58).

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7.3.3 Contestation Over Fitness For Work

The last two returners are working in General Practice. Their job status is different to the above respondents as they bring with them more cultural and economic capital which allows them to make different decisions about when they returned to work compared to the above respondents. Laura, a GP, has been living and working with secondary cancers since 2003. Laura challenged the advice from the occupational health adviser when he told her that she was 'fit for work' because she felt she was not. Smith (2006, p.118) in her work on institutional ruling refers to institutional discourse as:

> any widely shared professional, managerial, scientific or authoritative way of knowing (measuring, naming, describing) states of affairs that render them actionable within institutional relations of purpose and accountability (ibid).

Because Laura had acquired both cultural (her professional status) and economic capitals (insurance) she was fortunate in having a long period of time off work to recover. Although she was not able to return to her GP practice she was able to retrain in the field of contraception and sexual health. Her occupational health adviser, despite her having metastatic breast cancer, was of the opinion that she was fit for work even though Laura had undergone harsh programmes of chemotherapy which had affected her badly, over her long-term sickness absence from her original work. In Laura's case, there seems to be a difference in how occupational health understand wellness and someone who is 'fit for work' compared to Laura's reporting as a GP that she was not back to normal because

the chemo had affected her badly. Working whilst not fit-for-work is problematic for women with breast cancer. The following section shows how some businesses construct notions of presenteeism, but what are the practical effects for workers of these new discourses.

According to a blog posted by Health Management Limited,[40] there are problems with workers who present themselves as fit-for-work when in fact they are not fit to do their job. This is referred to as 'presenteeism' which is said to reduce productivity. The Work Foundation suggest:

> Presenteeism is said to account for 1.5 times more working time lost than absenteeism – and if someone reports to work while unwell, they will not work as effectively as if they were fighting fit (Health Management Limited).

According to Robertson Cooper[41], a business psychology company, in a report on employee engagement and wellbeing, they found that workers' productivity levels for employees who feel ill drops from 75% on 'normal days' to 55% on 'sick days'. As well as affecting productivity this also affects the morale and productivity of healthy employees.

However, as a GP and with personal experience of multiple chemotherapy treatments over five years for her metastatic breast cancer, Laura was well aware of the cognitive effects that had left her feeling that she was "not 100% herself". The chemo had "affected her badly". Despite being told she was fit for work Laura knew her own body and what she was capable of. As a main breadwinner, she was forced to rethink her RTW. In Laura's position, presenting for work as a

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[40] See http://fitforwork.org/blog/is-presenteeism-an-issue-in-your-workplace-part-one/

[41] Seehttp://www.robertsoncooper.com/103-news/167-presenteeism-on-the-rise-as-an-estimated-quarter-of-uk-employees-admit-to-working-when-ill

GP would not have been a viable option despite her Insurance assessor suggesting that she was fit for work.

In contrast to Laura's case, Elizabeth, a GP, aged 53 experienced a RTW that offered support. Initially she was worried that she wouldn't physically be able to cope with going back to work but was determined to keep active. As she got to the end of the year and knew that her locum insurance policy was running out, she started to prioritize her return by setting a date to return. But as this date loomed she started to worry. She asked to be referred to occupational health.

> The occupational health consultant said I think it is reasonable to negotiate that you go back to work initially on a flexible basis and that you just do so many sessions. After several meetings with the practice manager and some of the other staff, we set a return date. Before I went back I had some more training again on the computer…just before I stopped work, they had just changed over the IT system and it was horrendous… I was in this real panic about not being able to print off a prescription because I didn't know how to do that. It was making every consultation so much longer. (Elizabeth)

On her return, Elizabeth was offered training on the use of the IT system and went on a study day. She was given time to adjust to changes and attended practice meetings to familiarize herself with some things that were going on in the practice. But she stated that she felt anxious when she first went back. However, because everyone was really supportive and understanding and nobody tried to offload lots of extra things onto her she was gradually able to let things fall into place again.

Elizabeth was aware that chemotherapy has affected the way she works although she never discussed these types of problems with her consultant. Cimprich et al (2010) state there is a growing body of evidence to suggest that cognitive deficits are associated with chemotherapy after breast cancer. Their study found that patients who were tested were slower and less accurate in performing tasks compared to the healthy control groups. They examined selective attention which is the ability to focus on a particularly piece of information in a given situation whilst ignoring other information. Selective attention provides inhibitory

control for many aspects of cognitive function including working memory, learning, and higher order 'executive' functions such as decision making, problem solving, and effective social functioning.

7.3.4 Gender and Emotion Work in the Workplace

This section looks at the ways gendered structures are organized in the workplace and how they impinge on managers'/employers ability to satisfactorily deal with women returning to work after breast cancer.

Nettleton (2006, p.40) cited Blaxter (1990) who found that "women were more likely than men to offer expansive answers when defining health, and were also more likely to include social relationships in their definitions" as Louisa outlines below.

> I work in a 100% male environment and I have worked hard to get where I am. Suddenly to be made to feel oh, you've got a woman's disease. Nobody knows how to talk about it or what to say. Some people were kind – I guess they were thinking well that could be my daughter or mother. It's quite a lonely thing – you feel like a leper (Louisa).

This resonates with some feminist thinking that "silence and invisibility go hand in hand with powerlessness" (Smith, 1980 cited in Wilkinson and Kitzinger, 1994, p.135). When Louisa reported feeling fragile and isolated because her male colleagues didn't know how to talk about her cancer, she stressed:

> They are going to have wives, mothers and daughters going through breast cancer and it's not just about the work place. This is a big company with lots of women – I have no idea whether any women downstairs have been affected by it. I would like to play a role in talking about my experiences if anybody was prepared to listen (Louisa).

Louisa told her line manager about her breast cancer on the day she was diagnosed and was "disappointed initially with his reaction because he couldn't

offer me any assurances and I didn't know what this was going to mean in terms of my job and my work". Although Louisa states that her line manager was new in his post, he had no idea how to manage the conversation:

> He [manager] said, I honestly don't know how it is going to affect you. I was looking for reassurances that I was not going to lose my job so I rang HR and they were very helpful. They said well I don't know of anybody who has been sacked for having cancer. Do you want me to ring your manager and help him through this to let him know what is available? Thank goodness they did because he was hopeless. It is not particularly his fault but it was a difficult time (Louisa).

Equally incapable of offering support was Judith's manager:

> I think he was embarrassed. He is a nice man but I don't think he had any training in dealing with that kind of thing and I don't think he felt it was his role (Judith).

Judith felt she received more support from her female colleagues and said they were nice people to be around. Her comment that her manager did not know how to talk about such an emotional subject lends some support to Olesen (2000, p.321) who states that there are:

> "deeply embedded and highly significant social and cultural elements [that] influence gendered emotional experience and expression" [and that emotion is a] "social product, not a biologically embedded one" [but the correct] "doing of emotion" [is exhibited in specific contexts].

The experiences of the women going through breast cancer cited in Organization B and C above seem to have helped managers and staff understand emotional expression, and can contribute to the understanding of the needs of women returning to work after breast cancer.

7.3.5 The Precarity of Women's Employment After Breast Cancer

By precarity of employment [42] I refer to those workers who are denied permanent employee rights even though they may fill permanent job roles. This group of workers are more likely to be women, minorities and migrant workers on low wages – their working conditions are unstable and often dangerous. They are more likely to have reduced or zero capital. Little is known about the RTW of immigrant and minority women with breast cancer although Blinder et al (2011, p.763) suggest "employment status is related to treatment recovery and quality of life in breast survivors". This section looks at the precarity of employment contracts and how it impacts women working with breast cancer.

Pauline and Louisa were on permanent full-time contracts. Pauline knew that her employers offered six month's full pay and six months half pay and that she had just gone into half pay when she returned but there was no discussion about entitlements within her job contract. However, Louisa found it difficult to get information from her manager about how breast cancer would affect her future employment – she was uncertain as to whether she would lose her job because of her cancer.

Judith, a college lecturer and teacher manager (combined hours 18.5), showed concern about the increased number of people on zero hours' contracts which she says adds to the stress with the workload being added to and wages not rising. Judith's position is permanent but Tracey, who is a teaching assistant, faces an uncertain future in her work. Although she is on a full-time temporary contract when she went back after six months her job was re-located in another school. Her contract is temporary, zero hours, so when one child leaves her employers are under no obligation to renew it although she says they usually give

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[42] http://www.laborrights.org/issues/precarious-work

a month's notice. She feels lucky to be employed and states she is in no position to challenge her manager over the comments she made about being 'tired too' in case her zero hours' contract is not renewed. Her employment position and her health are precarious which adds to the emotional stress of returning.

Low paid workers and those on zero hours' contracts suffer additional stress as the following bloggers below report. During this research I visited on-line blogs for cancer patients over a two-year period. I regularly monitored two sites, Macmillan Cancer Support and Breast Cancer Care for comments on RTW after breast cancer and workplace experiences. Posted on a recent Macmillan blog, a patient reported:

> I have been back to work for a year now and still struggling, as soon as I returned my employer put me on a performance improvement plan, leaves it for a few months then starts again. Without Macmillan supporting me I would have folded but as a lone wage earner leaving is not an option…The stress created by HR and my manager is delaying my recovery but they seem unaware of the impact. I feel they are going through the process to get rid of me (Posted by Sonjajo 5 Nov 2015 5.09 PM).

Amanda posted:

> …I am three years post diagnosis and on my return my employer actually made me redundant!!! After scraping myself up from the floor, I've now found a new role but to be honest this employer is only marginally better, even though I declared from the outset. So many people find it increasingly difficult a) to admit that they are struggling and b) to get employers to look past the 'but you look well, so you are well' mentality (Posted by Amanda a01 5 Nov 2015, 6.22PM).

This blog caused an angry response and a reply from Rupert:

>…Once again the British Employer refused to acknowledge genuine illness and the need for individual return to work plans…you are covered by the Equalities Act but this current Govt. has watered it down so much that whilst you are protected as a Cancer Patient under the disability guidelines…an employer can and often does put the needs of the business way ahead of the individual. (Posted by Rupert66 on 5 Nov 2015, 7:37PM).

This blogger further suggested to the Macmillan Team:

>If you are reading these posts – this is a very serious and growing issues that really does need your engagement and involvement (ibid Rupert66).

Many bloggers go on-line just to offer support like Rupert66 above or seek answers to their problems with employers as the following blogger on the website of Breast Cancer Care shows:

>…I finished rads [radiotherapy] on 19 Oct, once again my underarm is sore. My boss has told me I have almost four weeks' holiday to still take and that if my doctor put me on a gradual return to work, I could work one day then have the next day off as holiday, or take two weeks' hols and then come back. Putting the emphasis on how my company sick pay has now ended, so I'll need the money! (Posted XX 29-10-2-12 12:21PM).

There are some bloggers on this site who talk about financial hardship and being forced back to work before they are ready. With pressures from employers and the fear of losing their jobs, many return unfit for work or not at all. One blogger reported being put under pressure from her employers:

>…I am feeling under pressure from work yet again! They have emailed me today to ask me to get my GP to convert a 'may be fit to work' to an 'unfit for work' note to cover SSP. I've checked direct.gov.uk and I think (as does my GP) that my current note is OK…I'm getting to the point where I feel I may have to resign but can't really afford to (Nicola, posted 23-08-12 08:54PM).

Organizational performance expectations on employees are evident in these blogs and are also highlighted in Kennedy et al's (2007, p.22) study where patients felt that their employers expected them "to perform" as normal after treatment which some found difficult initially on their return. References to needing time to get back to normal and employers expecting you to "put it all behind you" were problems that patients raised in Kennedy's study (ibid).

People working with cancer will continue to experience barriers to returning to work if there is no expectation on employers by government to support them. In a recent report, Macmillan stress:

> supporting people with cancer to remain in or return to work is the responsibility of both the Department of Health and the Department of Work and Pensions. It is essential that both departments work closely together. It must provide ongoing support once people with cancer have returned to work, as the first months back in work can be the hardest (Making it Work, 2010.p.19).

The report stressed:

> economic modelling commissioned by Macmillan has shown that if just half of the breast cancer survivors who initially return to work but then leave were helped to stay in work, the economy could save £30 million every year. These savings would come from things like decreased benefits paid to patients, and an increase in income tax paid to the government (p.15).

This was supported by the CEO of the Employers' Forum on Disability who said that it makes 'business sense' to support Macmillan's model and by "making reasonable adjustments, employers can retain their employees and allow them to perform to their potential". It helps "avoid legal risk" - Macmillan [43] have stated

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[43] Macmillan (2013) reported a "r*ise in the number of cancer patients experiencing discrimination at work. Employers are risking prosecution by flouting their legal responsibility to protect people living with cancer from unfair treatment and stigma at work". [Macmillan on-line prdcrowd.com accessed 2016].*

that employers have flouted the law.   Being disability aware can "enhance the performance of the organization and the individual in it" (p.13).

7.3.6 Support From Trade Unions

Both Pauline and Louisa, amidst their breast cancer trauma did not think of contacting their union reps because they didn't think they could offer help. However, it was not until much later when they had reflected on how they were treated on returning that they acted on these experiences. Pauline states:

> Maybe I should have got in touch with the union but I wasn't a rep then. It was because of the things that happened to me that I became a rep but the last thing I would have done was to have done something that made them possibly think that, you know, if they could get rid of me they would, so some of it was probably my fault I wouldn't push" (Pauline).

She became a union rep and put herself forward to become a wellbeing adviser because she wants to "hopefully make it better for other people (Pauline).

Judith is a union case worker at her college and says that although HR were 'pleasant' enough they were not very pro-active. She feels that although there is a sympathetic attitude towards cancer there is not the same tolerant towards stress or depression.   One of the reasons why she stepped down from her manager's role was because as a union member she wasn't prepared to ask people to do things that they were not contractually obliged to do:

> I think it was about how gung-go it was. There was a case of bullying with my line manager. When I applied for the management role I knew that the problem was there but I thought I could walk around it. I would have had to have fought hard if I had stayed in that role. But the problem became more intensified and the cancer to some extent made me think, I'm not going to do this (Judith).

7.3.7 Career Aspirations

Having cancer has changed attitudes towards work for both Judith and Louisa. On return, Judith stepped back from the teacher manager side of her job. She found this quite a pressure and wanted it 'off her hands'. Her class and capitals particularly in relation to household and gender relations allowed her to reduce her hours. She reported:

> I think I am very lucky to have a choice. Many people couldn't have afforded to go back down to a 0.5 and fortunately my husband is the breadwinner so I didn't have to worry (Judith).

She wonders if she had not been ill whether she would have fought harder to keep her manager's role. However, having cancer made her rethink her work priorities. She recognized that she was already suffering from stress and depression and was not prepared to add to this by taking on extra responsibility.

Louisa says she no longer thinks about promotion. She is quite happy working in her present role and focuses on building a life outside work – having a career has become less important. When I asked Louisa if the support had been there from diagnosis through to her return, would it have made a difference to her present attitude? She replied:

> Absolutely, hugely, it would make a difference. My long-term focus isn't about career progression any more – I no longer chase the next management position. (Louisa)

Things could have been different for Louisa if she had received more emotional support from the time she told her employers about her breast cancer diagnosis, through to her return with adjusting made to her work regime. She says,

> It happened from my diagnosis, not from my surgery…there is no allowance for that…no leeway because you are physically okay (Louisa).

Judith and Louisa downgraded their career aspirations because of their breast cancer but also because of the way they were managed on their return. Their stories support the findings of Maunsell et al (1999, p.472) who state,

> Having had breast cancer changed several women's feelings about the importance of work…work was less important now than before the diagnosis. The fear of becoming ill again, with the possibility of renewed absences, seemed to stop them from going after a new job or promotion.

Changes in attitude could be as a result of a physical disability, a lack of confidence to carry out certain tasks because of cognitive impairment or stress and depression. There is also evidence to show that organizational structures and practices that operate in relation to women's RTW after breast cancer can also create limitations for them in terms of the 'normal' expectations regarding promotion and progression. For example, Kennedy et al (2007, p.18) cites the work of Morell and Pryce (2005) who state:

> Patients who were not offered information about managing work issues associated with their cancer were four times more likely to report that their working lives had deteriorated because of the cancer.

Kennedy et al (2007) report that employers play an important role in supporting cancer patients and according to Blinder et al (2012, p. 768) act as gatekeepers for women's RTW after cancer. But if as Macmillan suggest in their report, *The Rich Picture of People of Working Age with Cancer*, that managers "lack awareness of the needs of people with cancer" and "do not have formal policies in place for managing employees" (undated:59) then how can they use their 'gatekeepers' role to facilitate women's RTW. Kennedy et al (2007, p.21) stress that some cancer patients feel coerced into returning to work before they are fit to return. The authors cite the case of how one cancer patient after a long period off work, was referred to an occupational health doctor:

> I returned…to work because he showed me the letter from the manager…there was an extremely strong unwritten, between the lines message, that if I didn't return to work they wanted me to finish.

This may simply be a matter of managers not having an awareness of support needs for people working with cancer. Some patients fear losing their job if they do not return soon after treatment. Additionally, if there is pressure on managers to report on the productivity of cancer patients' performance outcomes as Tatli and Özbilgi, (2012, p.183) suggest, then managing diversity places an ultimate emphasis on performance and attendance rather than making adjustments and rehabilitating employees back to work. Outsourcing health and wellbeing to private health care will not enhance managers' awareness of working with cancer. In fact, it may isolate employees from their managers because they are being dealt with by an agency outside of the organization i.e. they are being paid to deal with sickness absence, workplace stress and depression as a result of having cancer thus relieving managers of their responsibility to deal with these problems as part of their normal organizational management role. This distancing creates an invisible problem – one without a face or a name if managers have no knowledge of who is working with cancer and what their needs are.

7.4 Conclusion

This chapter has explored the cultures and practices of five major employers in the South West of England who have provided key information about how national policies and practices are implemented within their organizations with a focus on women returning to work after breast cancer. However, what these organizations are saying does not always reflect the narrated reality for some women working with cancer. My breast cancer respondents suggest their employers lack understanding of how to support women's physical as well as mental disabilities, and therefore experienced negativity from managers or little support in returning to normal working practices (see also Kennedy et al (2006). In support of this evidence Macmillan (2013) say that 'employers are flouting the law' by not making provision for a safe RTW for their employees under the Equality Act.

The above research data has highlighted that even though legislation and policies are in place to protect workers returning to work after breast cancer, we cannot assume that organizations will apply these in practice - a lot depends on how it is framed. The employers' responsibility to protect disabled workers is to some extent being placed in the hands of private enterprise which removes the impetus of managers to understand their duty of care to support women's RTW after breast cancer. Out-sourcing to private companies could result in support for returning breast cancer patients becoming more disjointed. For example, some HR Managers interviewed could not talk about a breast cancer case study because they are removed from this responsibility. Furthermore, my evidence shows that private health companies do not distinguish between the type of cancers in the management of health care they provide for organizations which not only homogenizes illness and disability but also adds to the lack of knowledge and understanding that employers have about the problems women face from diagnosis to a return to work. These problems will continue to be hidden from view if there is no discussion or adjustments made for a safe return. This chapter has shed some light on how institutional ruling impacts the lives of those RTW after cancer.

Chapter 8 Conclusion

8.1 Project Summary

This research project began with an exploration of the rising incidents of women's breast cancer and how this impacts their working lives. With more and more women being taken out of work either on a temporary or more permanent basis, women's lost employment has become a gendered health inequality. Their inability to participate in work and a loss to the economy is just not sustainable. There are many reasons why women are prevented from returning to work after treatment – some are too ill and are forced to retire due to ill health whilst others face barriers within the structural relations of organizations where managers fail to understand the disabling nature of the disease and fail to facilitate a safe return to work. **Chapter one** provided theoretical frameworks in which to place my research to examine how dominant ideas are shaped using medical models of health and illness that are narrow but have continued to become privileged over social models. Placed within these dominant ideologies are constructs of disability with its limited categories under which people are expected to fit and comply. The binary language used stresses whether a person is either able-bodied or disabled, a cancer survivor or a person who has lost the battle against cancer. Normative standards under which we work, are incorporated into the modus operandi of organizational structures, evidenced in medicine, government and the media. **Chapter two** follows how these constructs are translated into policy and enacted by government agents/charities who support patients through cancer. Still following with normative themes of health and illness, **Chapter three** critiques scholarly work on women returning to work after breast cancer. The majority of these empirical studies position their research within clinical or management intervention frameworks which dominate the literature on RTW studies. Whilst some of the authors of these studies identify the barriers to return, they place no emphasis or responsibility on relations of ruling which is addressed in **Chapter four** as part of my methodology for this research. I examine how macro structures play out at a micro level of workplace policies and practices using interviews with 16 breast cancer respondents, interviews with HR Directors

from 5 major South West employers, government reports, charity documents and on-line community blogs to establish how the ruling relations impact women's RTW after breast cancer. Data findings and analysis are outlined under three separate headings in Chapters Five, Six and Seven. These follow the narratives of women's breast cancer diagnosis, treatment, recovery and their return or non-return to work. **Chapter Five** explores women's personal narratives of the disease and how this sometimes conflicts with dominant medical ideologies and models. The results of this chapter begin to show how breast cancer can be debilitating both physically and emotionally particularly when extensive chemotherapy and radiotherapy treatments and invasive surgery are undergone. There are changes to body image and sexuality all of which add to emotional stress that impacts the decision of whether or not women return to work which is outlined in **Chapter Six**. In this chapter the data shows how different employment status and cultural capital determine a woman's decision to return or not return to work. A woman's social position can affect the type of decision made after treatment and their attitudes to work. Support networks play an important part in this decision making process as well as attitudes towards work. Where there is no discussion or adjustment plans laid out by the employer for a RTW, the data shows that breast cancer respondents' attitudes towards work changed and in some cases led to early retirement or a change of career – usually down-grading to a less demanding role. Only a third of the breast cancer respondents interviewed in this project returned to their original job roles. **Chapter Seven** looked at the wider relations of ruling to determine how employers interpret and implement government policy, their workplace practices in relation to RTW and how their employees are managed working with breast cancer. Interviews with HR Directors showed that organizations use different frameworks to address workplace health and illness and a return to work after cancer diagnosis and treatment. Despite having policies in place to address equality and disability under the Equality Act 2010, the focus of these organizations was on short or long-term sickness absence managed by occupational health – some of which were outsourced to private agents who did not separate out the different cancers. This could be detrimental to understanding the needs of women returning after breast cancer. This chapter highlighted that

line managers and HR Directors are not communicating effectively with employees returning to work after cancer. They show little understanding about both the physical and the emotional stress that women with breast cancer face on their return. The lack of knowledge, understanding and attention paid to women's disabilities through their breast cancer is compounded by employers making no adjustments to facilitate a safe return.

Reflections 8.2

How has Smith's concept of relations of ruling and Bourdieu's social body and different types of capitals informed the analysis of this thesis? Firstly, Smith's work has been the driving force for this research focusing on the dominant mode of ruling in organizations whose rules affect the ways in which women have had to make their return to work after breast cancer. My research has shown how the logic governing the processes of these organizations is full of distortions, for instance hidden gender bias, and that women are excluded from these decisions making practices. Examining the position of women in the actualities of their everyday lives starting from their breast cancer diagnosis to their return to work using Smith's relations of ruling has allowed this research to follow what is important to women and to map what is largely unknown and which otherwise would be ignored. For example, the organizational logics of the medical world apply normalizing practices to women diagnosed with breast cancer who need a mastectomy and/or reconstruction. The exercise is for them to return patients 'back to normal' as soon as possible. One of the hidden distortions which this research found was that patients were under pressure to regain their feminine identity. For instance, Pauline (chapter 5, section 5.5) reported being rushed into making a decision about a reconstruction within 28 days. She was horrified when the surgeon showed her pictures of reconstructed breasts that did not match. She felt guilty for feeling this way. The rule that Pauline's surgeon applied was of a single concern to return her to a female shape. The constructed breast would be hidden in a bra but for Pauline, losing a breast was a personal loss that she had to learn to accept. The feelings of guilt and loss experienced by Pauline were not part of the surgeon's normalizing process. Similarly, Rachel (chapter 5,

section 5.5) experienced problems with a second tumour hidden behind her original reconstructed breast implant that had ruptured. These issues are normally hidden and make women feel vulnerable after a mastectomy (Lorde, 1988, p.33). Janette (chapter 5, section 5.5) had problems with her changed body image and sexuality – she underwent a double mastectomy and went from "large breasted to hollow breasted" and desperately wanted to fit in with her athletic colleagues. Drawing on Smith's notion of hidden gender distortions within organizational logics, provided a means of analyzing my respondents' experiences and widened our understanding about body image as Bouquiren et al (2013, p.2178) state is a "multifaceted construct" which not only involves individual feelings about the body but also its "wholeness, functioning and sexuality".

Other gender distortions which are hidden from view are the rules that are applied to women like Rachel (chapter 6, section 6.3) who had time off firstly for breast cancer then Hodgkin's disease. She felt she was "being bullied...and felt so totally unsupported" by her employer. She further acknowledges that her depression was more to do with her "experience of bullying rather than the tablets she was on for breast cancer". What was uncovered in analyzing the logic of this organization's relations of ruling was the lack of any system in place to assess Rachel's RTW process, resulting in poor work relations and eventual redundancy.

The logic applied by other organizations in their relations of ruling can also be witnessed in those who fall between the different categories of benefit claims like Janette (chapter 6, section 6.3). Living alone as a single woman, Janette lost her financial independence after she was made redundant the day before she was diagnosed with breast cancer. She experienced the hidden bias contained in both the rules of her insurance company with regard to a claim for a redundancy payout, and also in claiming benefits.

Smith stresses we must question taken for granted knowledge and that "knowledge must be differently written and differently designed if it is to bear other social relations than those of ruling" (Smith, 2004, p.94). This can prove difficult at times because we are both in and of the social world and are, in the main, abstracted from our local settings (Smith, 2004, p.50). Thus, we are separated from what we know as individuals because we are trained to know what is external to our practical lives.

Exploring the social relations involved in ruling work Smith (1990b, p.6) describes the specific ruling functions and how these are accomplished, organized and controlled:

> They are those forms that we know as bureaucracy, administration, management, professional organization, and the media. They include also the complex of discourses, scientific, technical, and cultural, that intersect, interpenetrate, and coordinate the multiple sites of ruling.

For instance, in chapter 7, I explore both the institutional language used by HR directors and show how their organizations manage women's RTW after breast cancer - how they draw on various frameworks which results in different approaches and practices on how each organization managed the process. It has highlighted that managers of organizations at a local level do not fully understand the specific needs of breast cancer patients as they return to work and that there is a need for better training so that managers can communicate effectively to make adjustments to help women return.

Bourdieu's concept of habitus, field and capitals has also provided a useful framework in which to analyze how class affects both treatment options and depending on my respondents' employment status, the length of time taken to recover. Starting with the habitus in which the body is in the social world and the social world is in the body, Bourdieu describes how each class learns the rules of the social game (Bourdieu, 1981). Actors exhibit attitudes, tastes and ways of being which become so internalized that these are almost forgotten. But within

this embodied history which Bourdieu refers to as a collection of personal and social history, it leaves a trace that allows us to view how the social body is organized. So, when there is a clash of attitudes and inequalities these are often marked in distinctions or divisions of class, race, gender, sexuality and disability.

The habitus is relational and only makes sense in the context of specific fields (Bourdieu, 1996, p.264). He sees the field as a structured system of occupied social positions and also a system of power relations operating a dominant/subordinate homology to one another. These allow or permit goods or resources, which Bourdieu separates into different categories of cultural, social, economic or symbolic capitals, to exist in relation to the field. Cultural capital is best described as how ideas of the dominant classes are legitimized and presented as universal because these players hold positions of power (Bourdieu, 1991, p.14). Drawing on these insights for instance, in chapter 2, I explore how cancer charities play an important role in supporting government health initiatives. These ideas are incorporated into government policy and are then taken up by HR Managers in organizations who use the official language of equality and diversity (see chapter 7 section 2.3.)

I have also explored Bourdieu's notion of how individual agents can possess specific capitals, both cultural and economic, which provide access to resources. My research found that women were differently positioned in terms of their job security and the facilitation of their RTW which was dependent on the type of employment contract they had. For example, Shirley, (chapter 6, section 6.3) was a manager for post office counters on £6.50 an hour and entitled to statutory sick pay. She returned whilst having chemotherapy and radiotherapy because she did not know she was allowed time off for treatment. Shirley's lack of capitals, both cultural and economic resulted in her taking a cleaning job after a dispute over sick pay. In comparison, Laura (chapter 6, section 6.3) and Elizabeth (chapter 7. Section 3.3) both GP's, were able to take a considerable amount of time off work to recover from treatments because they were covered by private

insurance. Elizabeth was eased back into work gradually and received training to update her skills. Because of her cultural capital and support networks in the field of medicine, Laura was able to retrain in another field of medicine. Bourdieu suggests we hold more capital if we are supported by networks within the field to maintain relations of power (Bourdieu, 1996, p.265).

Smith's work on relations of ruling has many similarities to Bourdieu's theory of social practice. Both highlight how there are hidden distortions within the invisible ruling relations. These are established divisions between the sexes and labour (Bourdieu, 1977, p.87; Smith, 1987, p.54). Both believe the logic of organizational practices are abstracted and generalized - they come to us from outside and not from our own experiences. I turn now to show how these concepts have informed the analysis of my findings and how this in turn has enabled me to critically reflect on these concepts.

Having a breast cancer diagnosis starts with knowledge construction where women piece together information about the disease. To help them do this they enter different fields in which they have a relationship with the players in that field, for instance in medicine, cancer charities, government department and the media. Some may even become familiar with pharmaceutical companies, for instance my respondent who was a GP was offered a new drug trial. For those respondents who return, they are exposed to their respective organizational practices which may be differently organized from that of hospital or charity field logics. For example, in chapter 7 my research shows that because of the various frameworks used, each organization focuses on disability and breast cancer in different ways which in turn results in different levels of support. For some women, there is little or no support on their return to work which, in some cases, leads to a decision not to return or decisions to reduce job roles/hours. However, this does depend on their cultural and economic capitals - i.e. their job status and type of employment contract. For instance, respondents on zero-hours contracts had to return to work as soon as they could because they feared that they would

not have their contract renewed. For those respondents who did not return some were subject to another set of rules governing the Department of Work and Pensions and Benefits agencies - another relational field (see Janette outlined above). Players experience different relationships in these various fields depending on their access to capitals (see Judith, chapter 7 section 3.2). Here, the concept of the social body becomes important in terms of how respondents navigate their way through these institutions. We are not only marked by class but our positions in the social structure which affect the way we manage our health, is intersected by other categories such as gender (Glenda, chapter 5, section 5.4), race (Rosemary, chapter 5, section 5.4), sexuality (Janette, chapter 6, section 6.3), age (Laura, chapter 6, section 6.3) and disability (Evelyn, chapter 5, section 5.4; Ruth, chapter 5, section 5.4; Tracey, chapter 7, section .2.4; Louisa, chapter 7, section 3.1).

In this research, I have highlighted the gaps in the existing literature on RTW by examining the wider relations of ruling under which women are subjected through workplace practices. My research found that organizations also use different ways to address sickness absence, often managed by outside agencies which further distances managers from understanding the disabilities that breast cancer patients face. Additionally, some employees are expected to perform as normal after treatment and are treated unfairly by their employers. (see Rachel, chapter 6, section 6.3.) They are not supported because managers are not aware of the physical and psychological problems caused by breast cancer surgery and treatment regimes. Managers are not able to discuss these problems with their staff.

8.3 Theoretical contributions and limitations

This research addresses practical and pragmatic contributions but also makes a significant theoretical contribution drawing on Smith and perhaps to a lesser extent, Bourdieu. It draws on insights from both the feminist sociology of health and embodiment on the one hand, and the sociology of work on the other which

is still rare in researching cancer, disability and illness. Focusing on gender, work embodiment and health has shed light on how each of these elements intersect the social body. Exploring the practices of power within the textually-mediated relations of ruling brings the two disciplines together and shows the importance of how the 'sick' body is also a social body as it returns back to the world of work. Just as we cannot leave the social at the door when we become sick, we cannot ignore the disabled body as we take it back to work after breast cancer - as Probyn states "the body does not fall away before the social...the social is charged with physicality (Probyn, 2004, p235).

The significant contribution that this research makes by linking the sociology of health and illness together with the sociology of work is that it has highlighted the need to move beyond the "interchanges of frontline settings" (DeVault and McCoy, 2006, p.28-29) exploring institutional language and practice to investigate what actually happens to women when they RTW after breast cancer. For example, during the interview process with HR directors I moved the interviewees on beyond what they are trained to say and the concepts they use (see discussion in Chapter 7, section 2.3) which started to uncover how the relations of ruling impact workplace health and practices for my breast cancer respondents. Health and work cannot be separated. If they are, we cannot tell the whole story. Women cannot leave their sick bodies at the door of their workplaces on their return to work after breast cancer. The women's narratives outline the experiences of their sick body, their changed body and their social body which I have analyzed using Bourdieu's concept of habitus field and capitals. The idea of thinking health and work together is illustrated in the following examples. Some breast cancer respondents reported that employers expected them to work as normal when they returned and did not recognize that treatment regimes can lead to cognitive impairment or other physical disabilities like lymphedema. In chapter 7, section 2.4, Tracey states that her employer lacked understanding and concern for how she was fatigued after treatment. Employers expect their workforce to embrace the wellbeing agenda when they are already under stress as one of my breast cancer respondent's stated, "more

people are under stress...with less tolerance [towards] mental health...[asking] why aren't you more well? (Judith, chapter 7, section 2.4). Other examples of respondents suffering emotional stress with little or no understanding from their employers were reported by Pauline, Louisa and Tracey in chapter 7, section 3.1. Louisa stated that her employers "underestimated the magnitude of the emotional trauma and don't see it as a disability". As we examine the text-mediated relations as part of the relations of ruling there appears vast differences in the way in which disability legislation is interpreted and implemented through workplace policy. Some employers have little or no provision in place to make adjustments under the DDA and Equality Act 2010

Although some studies identify environmental factors in terms of work ability and demands, there is no analysis of how breast cancer patients are affected by workplace practices which function as part of the relations of ruling of organizations. Whilst some studies recognize that there is a 'culture of ignorance' (Kennedy et al, 2007, p.22) within organizations, they mostly call for intervention trials. But as I have argued in chapter 3, section 3.2.2, before intervention strategies are put in place, we need to fully understand how the structural relations impact on women with breast cancer returning to work. For instance, there is little value in introducing wellbeing agendas in the workplace if we do not understand how and why this is practiced. Edwards and Imrie (2008) suggest that employers see the wellbeing of staff as the responsibility of the individual but as Atkinson (2013) suggests, it depends on the mobilization of resources. Therefore, we must challenge the line of argument of the wellbeing concept and its taken-for-granted health benefits.

The aim of this research was "to make women's lives visible" and help to affect change in their working lives (Harding, 1987, p.8). Feminist research places women centre stage in the research inquiry. Using gender as a lens focusing on workplace health and wellbeing, this study fills a gap in the literature and contributes to knowledge about RTW after breast cancer from a sociological perspective in a way that has not been focused on before. I hope that this

research will form the basis for other inquiries about working with cancer and will be used by policy makers, charities, managers and academics across disciplines.

The literature reviewed for this research project sits across a wide range of disciplines. There is an abundance of empirical research with a strong focus on breast cancer and RTW using medical models of health or sickness absence intervention strategies for the purposes of insurance management but these are narrow. To date, and to the best of my knowledge, my research is the only study from a sociological perspective which focuses on how the ruling relations of institutions impact the working lives of women who return or do not return to work after breast cancer. Gendered health has been missing from the study of women's occupational health and workplace wellbeing for many decades it seems. Researchers like Messing (1998, p.70) have spent many years researching why there have been difficulties in getting the attention needed to focus on women's occupational health, arguing that sickness absence literature "exemplifies the field's support for the employers' perspectives" which my data supports. Additionally, across the clinical literature, absenteeism is more often than not classed as a behaviour problem rather than a health and safety at work issue due to poor working relations. Messing points out that it has been difficult to get funding to study women workers' health problems. She states, "the fact that few studies exist creates an image of women's work as safe, which in turn militates against funding to study it" (Messing, 1998, p.71). Within the existing literature available in studying women's RTW after breast cancer none explore how structural relations impact a RTW after breast cancer or how employers put in place policies and procedures to accommodate workers' disabilities under section 20 of The Equality Act 2010 regarding reasonable adjustment (Appendix D). Macmillan suggest that employers are flouting the law regarding workers with cancer but we do not know what this means unless there is an exploration of managers' understanding and attitudes towards women working with breast cancer and their disabilities created through surgery and treatment which may require adjustments to be made to working practices to facilitate a safe return to

work. I have begun this exploration on a small scale but further work needs to be done.

In 2014 it was reported that breast cancer was the foremost cancer in women with over 55,000 new cases diagnosed compared to 3,224 cases of cervical cancer and 7,378 cases of ovarian cancer. Whilst breast cancer shares many of the same characteristics as other forms of cancer and disability, for women returning to work after breast cancer there are important specificities related to women's sense of their gendered identities. The rising incidents of breast cancer is of concern not only to medical professionals (regarding the cost of treatment) but also to sociologists of health and of work because of the increasing number of women being taken out the workforce either temporarily or permanently sometimes due to the disabling effects of treatment. Maunsell (1999) reminded us that the same problems occurred two decades ago with employers ignoring disability legislation and yet the same breast cancer issues are still being reported in current RTW studies. It is imperative that future researchers learn from what has already been reported and do not ignore how disability legislation is being interpreted and put into practice.

In conclusion, for women's employment to become sustainable, they should be able to make a safe return to work after breast cancer treatment. My data shows that employers need to ensure that their managers have adequate knowledge and understanding of what the Equality Act requires of them and a wider understanding of what it means to support disabled employees with breast cancer. Improved communication is essential to support women returning and employers need to recognize their duty of care, effective from diagnosis to return to work.

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Appendices

A - Interview Schedule for breast cancer respondents

Introduction - informal

Thank the respondent for agreeing to participate and remind them that the interview can be stopped at any stage if they don't wish to carry on. This also extends to withdrawing from the project at any time.

Thank the respondent for agreeing to participate and remind them that the interview can be stopped at any stage if they don't wish to carry on. This also extends to withdrawing from the project at any time.
Explain that the interview is in two parts – part one is to record some general characteristics and Part two is their story.
Reassure the respondent that the data will be anonymised and kept confidential.
Ask if the respondent has the support of a health Professional such as a breast care nurse at present

Part one

 First task (formal) write and record answers to questions, work related and disease related characteristics

Part Two

Second task (informal) – the story

Introducing topic questions can move backwards and forwards from informal to formal

Topic questions

1)   The diagnosis
Can you tell me about your breast cancer diagnosis – what were your feelings at the time?

What knowledge did you have about breast cancer prior to diagnosis?

What Professional advice did you receive – how were treatment options explained?

What professional support was offered?

2)   Return to Work
 Can you tell me about your Conditions of work on your return?

How soon did you tell your employer?

Did your employer offer a back to work plan?

Were you able to work during treatment? – how did you manage treatment/ appointments: e.g. time off work and work load schedule?

Did your employer discuss sick leave, contract hours, reduced hours, work ability, rehabilitation?

Did you receive support from your line manager and work colleagues? Was there an understanding of your needs? Can you tell me more about their attitudes?

3) **Post treatment** – Can you tell me about the support you received both from your employer and from other support networks such as family/friends and cancer charities. Overall, how has breast cancer impacted on your working life?
   Has it changed your attitude towards work or the type of work you do?

B - Consent Form for interviewees

WORKINGLIVES
RESEARCH INSTITUTE

PARTICIPANT INFORMATION SHEET

Research project title: Narratives of women's breast cancer experience and how this impacts on their working lives

Dear Participant

You are being invited to take part in a doctoral research project. Before you decide to participate it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask if anything is unclear or if you would like more information.

Aims of the project

The aim of this Doctoral research study is to record the personal stories of women who have been diagnosed with breast cancer in the last five years and explore how this has affected their working lives.

Research Objectives

- To explore women's personal experience and beliefs about breast cancer
- To explore how women's personal beliefs fit into the broader context of workplace practices
- To explore how women navigate their way back to work after breast cancer through institutional practices

Background

The rationale for this study is that each year over 55,000 women develop breast cancer which results in more and more women being taken out of work. This may mean a temporary or permanent loss of employment and/or work ability. Studies show there are a number of breast cancer patients suffering discrimination at work, some women are pressured into leaving their jobs after treatment because there are little or no support mechanisms in place to facilitate a safe return. There are also reports of a lack of sympathy or understanding about returners work ability (disability) directly from their employers but also from work colleagues who may have to shoulder extra work responsibility during rehabilitation periods. Whilst most women experience few problems returning to work - they want to get back to 'normal' after treatment and return to their jobs as soon as possible, there are those who struggle to retain their jobs. For whatever reasons women return or don't return after breast cancer, little attention is paid to how the wider social relations impact on their decisions. Sharing your experiences and contributing to the exchange of knowledge on this topic might help other breast cancer patients, their families and employers understand what working with breast cancer really means.

If you do decide to take part, please read the following information carefully.

Your involvement

I would like to interview women who have had breast cancer in the last five years living in the South West who are: employed full time, on part-time contracts, agency staff, self-employed, planning to return or have returned to work, or not returned to work for various reasons.

Interviews will be conducted face to face in your own home or by telephone and could last between 60 – 90 minutes and if necessary, might be followed up with a second interview. Questions will be formulated to focus on your breast cancer diagnosis, personal ideas about the disease, treatment regimes, professional advice received, support and advice from employers and if you agree, the interviews will be audio taped and transcribed verbatim (word for word). You are free to withdraw from the project at any stage of the process.

If you decide to participate in this study, your participation and any information collected from you will be strictly confidential, and only available to the research team of me and

my supervisors. Data will be erased from all files on completion and submission of my Doctoral thesis.

We would like to thank you, in advance, for your participation.

Doctoral Researcher: Dianne Dowling

CONSENT STATEMENT (please tick) yes no

1. I understand that my participation is voluntary and that I may withdraw from the research at any time, without giving any reason.

2. I am aware of what my participation will involve and I understand that there are no risks involved in the participation

of this study.

3. All questions that I have about the research have been Satisfactorily answered.

Do you agree to: **(please tick)**

The recording and transcription of the interview?

your organization being named as participating in the project?

 direct quotes being attributed to you by the above title?

Participant's signature:

Participants name (please print):

Tick this box if you would like to receive a summary of the results by e-mail ☐

E-mail: _____

Date: _____

Research Supervisors:

Dr Irene Gedalof, Senior Lecturer

Dr Leroi Henry, Senior Research Fellow

London Metropolitan University

166-220 Holloway Road, London N7 8DB   Telephone: 0207 71335132

C - Interview Schedule for HR Directors

Questions

In this workplace what are your Equality and Diversity Policies? Can you talk a little about this?

Where does disability fit into the overall policy?

Researcher Note: move through the stages

How prominent are the issues of disability in your brief and in your experience here?

Within Disability, how does a major illness like breast cancer fit into your understanding of people's rights and people treatment in the workplace within the Equality and Diversity framework?

You have already told me you have had one case of breast cancer so obviously without revealing too much that is confidential to that person, could you talk me through the process of what the challenges of that particular case were in relation to the policies and practices that were established and did it reveal anything that suggest that the policies might need to be further developed or expanded?

To conclude, if you were asked to reflect on this single case particularly in terms of the satisfactory implementation of equality and diversity policy that really includes and values people, what has been learned from this breast cancer experience?

End

D – Extracts from The Equality Act 2010

There are Currently outstanding changes being made to this act by government. The following parts have been extracted from the act as at 26th June 2010 with reference to the protection of women with breast cancer returning to work.

CHAPTER 1 PROTECTED CHARACTERISTICS
4 The protected characteristics

The following characteristics are protected characteristics—

* age;
* disability;
* gender reassignment;
* marriage and civil partnership;
* pregnancy and maternity;
* race;
* religion or belief;
* sex;

- sexual orientation.

5 Age

(1) In relation to the protected characteristic of age—

(a) a reference to a person who has a particular protected characteristic is a reference to a person of a particular age group;

(b) a reference to persons who share a protected characteristic is a reference to persons of the same age group.

(2) A reference to an age group is a reference to a group of persons defined by reference to age, whether by reference to a particular age or to a range of ages.

6 Disability

(1) A person (P) has a disability if—

(a) P has a physical or mental impairment, and

(b) the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities.

(2) A reference to a disabled person is a reference to a person who has a disability.

(3) In relation to the protected characteristic of disability—

(a) a reference to a person who has a particular protected characteristic is a reference to a person who has a particular disability;

(b) a reference to persons who share a protected characteristic is a reference to persons who have the same disability.

(4) This Act (except Part 12 and section 190) applies in relation to a person who has had a disability as it applies in relation to a person who has the disability; accordingly (except in that Part and that section)—

(a) a reference (however expressed) to a person who has a disability includes a reference to a person who has had the disability, and

(b) a reference (however expressed) to a person who does not have a disability includes a reference to a person who has not had the disability.

(5) A Minister of the Crown may issue guidance about matters to be taken into account in deciding any question for the purposes of subsection (1).

(6) Schedule 1 (disability: supplementary provision) has effect.

 (b)a reference to persons who share a protected characteristic is a reference to persons who are of the same sexual orientation.

20 Duty to make adjustments under the Equality Act 2010

(1) Where this Act imposes a duty to make reasonable adjustments on a person, this section, sections 21 and 22 and the applicable Schedule apply; and for those purposes, a person on whom the duty is imposed is referred to as A.

(2) The duty comprises the following three requirements.

(3) The first requirement is a requirement, where a provision, criterion or practice of A's puts a disabled person at a substantial disadvantage in relation to a relevant matter in comparison with persons who are not disabled, to take such steps as it is reasonable to have to take to avoid the disadvantage.

(4) The second requirement is a requirement, where a physical feature puts a disabled person at a substantial disadvantage in relation to a relevant matter in comparison with persons who are not disabled, to take such steps as it is reasonable to have to take to avoid the disadvantage.

(5) The third requirement is a requirement, where a disabled person would, but for the provision of an auxiliary aid, be put at a substantial disadvantage in relation to a relevant matter in comparison with persons who are not disabled, to take such steps as it is reasonable to have to take to provide the auxiliary aid.

(6) Where the first or third requirement relates to the provision of information, the steps which it is reasonable for A to have to take include steps for ensuring that in the circumstances concerned the information is provided in an accessible format.

(7) A person (A) who is subject to a duty to make reasonable adjustments is not (subject to express provision to the contrary) entitled to require a disabled person, in relation to whom A is required to comply with the duty, to pay to any extent A's costs of complying with the duty.

(8) A reference in section 21 or 22 or an applicable Schedule to the first, second or third requirement is to be construed in accordance with this section.

(9) In relation to the second requirement, a reference in this section or an applicable Schedule to avoiding a substantial disadvantage includes a reference to—

(a) removing the physical feature in question,

(b) altering it, or

(c) providing a reasonable means of avoiding it.

(10) A reference in this section, section 21 or 22 or an applicable Schedule (apart from paragraphs 2 to 4 of Schedule 4) to a physical feature is a reference to—

(a) a feature arising from the design or construction of a building,

(b) a feature of an approach to, exit from or access to a building,

(c) a fixture or fitting, or furniture, furnishings, materials, equipment or other chattels, in or on premises, or

(d) any other physical element or quality.

(11) A reference in this section, section 21 or 22 or an applicable Schedule to an auxiliary aid includes a reference to an auxiliary service.

(12) A reference in this section or an applicable Schedule to chattels is to be read, in relation to Scotland, as a reference to moveable property.

(13) The applicable Schedule is, in relation to the Part of this Act specified in the first column of the Table, the Schedule specified in the second column.

Part of this Act	*Applicable Schedule*
Part 3 (services and public functions)	Schedule 2
Part 4 (premises)	Schedule 4
Part 5 (work)	Schedule 8
Part 6 (education)	Schedule 13
Part 7 (associations)	Schedule 15
Each of the Parts mentioned above	Schedule 21

21 Failure to comply with duty

(1) A failure to comply with the first, second or third requirement is a failure to comply with a duty to make reasonable adjustments.

(2) A discriminates against a disabled person if A fails to comply with that duty in relation to that person.

(3) A provision of an applicable Schedule which imposes a duty to comply with the first, second or third requirement applies only for the purpose of establishing whether A has contravened this Act by virtue of subsection (2); a failure to comply is, accordingly, not actionable by virtue of another provision of this Act or otherwise.