

# **Anxious Times: A Discourse Analysis of Women's and Health Professionals' Constructions of the Experience of Breast Cancer**

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## ABSTRACT

Every day up to seven women in Aotearoa New Zealand are diagnosed with breast cancer. One in eight women will develop it at some time in their lives, and over 600 die each year, almost two a day (New Zealand Ministry of Health/NZHIS, 2014). In a culture where women's attitudes, thoughts and reactions towards breast cancer are consistently portrayed as having high emotional content, the likelihood that health professionals might experience emotion aligned to their work with women with breast cancer is also high.

Although a popular topic for media attention and women's personal narratives, few research studies have investigated breast cancer from the perspectives of both the women who have experienced the disease, and their health professionals. This study is different therefore, in its inclusion of medical practitioners. While not pairs *per se* as doctor and patient, the perceptions of 17 health professionals were explored alongside the perceptions of 20 women through their constructions of the same discursive object, breast cancer.

Two key questions were central to the study: (1) what were the discourses most predominantly deployed by women and health professionals through which they constructed breast cancer, and (2) what effect did the participants' positioning in these discourses have on their subjectivities and their discursive practices?

The methodology for the study was post-structuralism, drawing on French philosopher Michel Foucault's concepts of discourse and power/knowledge. The findings showed two dominant discourses by which the women and the health professionals constructed breast cancer – the medical discourse, and the gender discourse. Breast cancer was constructed in medical and gendered ways as problematic, dangerous, and not straightforward. Application of Foucault's notion of governmentality showed that through their deployment of these dominant discourses, women's and health professionals' behaviour was controlled and conforming. As a result, the emotional impact of breast cancer on both parties was not well articulated or understood, and was shut down within medical encounters.

The findings showed further that the intersection of these two discourses produced significantly anxious or fearful subjects. These findings have important implications for

women, and for the education of health professionals who work in the field of breast cancer. This study complements other earlier research which has found that women are fearful of breast cancer and its ramifications, and that there are also associated tensions for health professionals.

Two major recommendations for further investigation, and for education, are: (1) permitting women to communicate more openly with their health professionals, and (2) educating professionals in critical thinking and analysis. This might facilitate better understanding of the meaning of breast cancer for each party, thereby steadying the balance of power between the two through a commonality of discursive construction. The significance of the study is that it opened up opportunities for other discourses and discursive practices to be brought into play, thus creating spaces for additional subjectivities to be heard and recognised.

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## ATTESTATION OF AUTHORSHIP

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signature: 

## DEDICATION

This study is dedicated to the spirit of my maternal grandmother, Evelyn May Birch, who under-went the Halsted Radical Mastectomy, but lost her life to breast cancer in 1940, aged 41 years.



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A project such as this can never be achieved by one person only, and on its completion there are many people to acknowledge and to thank.

I offer this work with deep appreciation to ...

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... my family, friends and colleagues, who supported me in so many ways, often unspoken, often unknown by you, and often unacknowledged by me. Thank you for understanding and accepting my 'unavailability' over the course of this study,

.... the memory of my maternal grandfather Papa Birch, who taught me his meaning of 'thesis' all those years ago,

... the memory of my parents Max and Nancy Stevenson, who instilled in me the valuable lesson of 'having a go', which has often got me into enterprises well over my head, but which in their pursuit has also strengthened me.

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

Susan Sontag  
*Illness as Metaphor*

*And of course, I am afraid – you can hear it in my voice – because the transformation of silence into language and action is an act of self-revelation and that always seems fraught with danger.*

Audre Lorde  
*The Cancer Journals*

*At 2.45pm I walk quickly  
To the reassuring cover of pohutukawa.  
Two minutes silence in your honour  
While you lie in white and green under bright  
lights.  
You are strong and brave, and your friends wait out  
this life squall  
Until you are again in calm waters  
And the pohutukawa blooms for summer.*

DM, August 2011

## CHAPTER ONE: INTRODUCTION

One in eight New Zealand women will develop breast cancer at some point in their lives, and every day seven New Zealand women are newly diagnosed (New Zealand Ministry of Health (2014a)). Because of its high incidence, breast cancer has a large profile, and much has been written about it. I became one of those statistics and lived through my personal breast cancer story. As a result of my experiences, I became interested in exploring accounts of interactions between patients and the health system – what I term throughout this study as ‘the medical encounter’. I became focussed on exploring how the phenomenon of breast cancer is portrayed today, and how it is talked about by women and the medical profession. Breast cancer is presented as a biological fact that particular changes to breast tissue occur. This phenomenon is called ‘breast cancer’ because the medical discourse is most generally drawn upon to name it as such. I was interested in exploring if, by its very naming as cancer of the female breast, there might be some impact on the social interactions within medical encounters, and sequentially on the behavioural and emotional reactions of the people involved. My own experiences as a woman diagnosed with breast cancer, and my subsequent interactions with the various health professionals and oncological technology, highlighted for me the changing nature of one’s subjectivity over the course of discovery, diagnosis, treatment and recovery from the disease.

### **My Personal Experience**

Even before I was diagnosed with breast cancer, I was aware of the high profile and presence of the disease. Indeed, the one in eight seemed very close to home for me because all of the women in my social groups knew of someone who had had breast cancer. I personally was close to several women who had been diagnosed and treated for breast cancer, and had witnessed the physiological changes or *cachexia*, (weakening or wasting) associated with terminal cancer. Some of these women had literally died before my eyes. As a group of friends, relatives or colleagues of these women, we had been party to many accounts of the circumstances of diagnosis; encounters with a range of specialists, specialists with whom one ‘connected’, liked and trusted – or otherwise; experiences of disfiguring surgery, nauseating chemotherapy and the ‘red-necking’ of burning and debilitating radiation treatment. Dilemmas over full or partial mastectomies and breast re-constructions were also openly discussed. We joked about the indignities, pain or discomfort of the ‘squashed boob’ in the process of mammography, and we

sympathised with those undergoing multiple surgeries because ‘the margins weren’t clear’. We supported our friends in consultations with surgical brassiere experts and wig fitters, and commended and praised the first tentative outings of the new prostheses, head scarves and wigs. Libido and sexual touching were affected, relationships strained and marriages broke up, seemingly with breast cancer as the major culprit. We saw the passing of the trinket bracelet charm from one ‘Breast Friend’ to another, became involved in breast cancer appeals, and bought *Pink Ribbon* products. Among the women with breast cancer there seemed to be a strong camaraderie of mutual interest and support. Having breast cancer, in fact, seemed to be a badge of honour for a club of womanhood, an extension of the bond of shared experiences that are exclusively womanly – pregnancy, birth, and the rituals, practices and problems of the female body. While I was interested and supportive, it was a club that I hoped I would never have to join. This was in no small part due to my belief in medicine’s construction of breast cancer as a common event, one which continues to kill or at least maim a significant number of women known to me.

This study primarily came about as a result of my being diagnosed in November 2004 with *ductal carcinoma in situ* – cancer of the breast. At the time I was in my mid-fifties, a divorced, mother of no live-birthed children, a professional woman, a registered psychologist who had practised for fifteen years in the education sector and who had been in the teaching profession for eighteen years before that. I was a marathon runner and swimmer, and enjoyed general good health. So, while it might be considered that this introduction reads like that of any other woman’s narrative of her ‘breast cancer journey’, the inclusion of my personal details in setting the context for my study are important in light of what my research reveals about current and enduring breast cancer discourses. I had learnt from medical and everyday media that there seemed to be a strong genetic link to breast cancer within blood-related females. I knew that my maternal grandmother had died of breast cancer in 1940 at the age of 41. We have photos of her taken after her Halsted Radical Mastectomy, with her chest flat on the left side. I knew that she had had gynaecological problems – two baby sons deceased, and my mother the sole survivor. I have no children, experienced early menopause, and had undertaken hormone replacement therapy for a few years before ceasing it. I had had the same male GP for over 25 years, in whom I had implicit trust. Together we were vigilant in scheduling regular breast examinations and mammograms because we were both aware that my medical and genetic history included several epidemiological and



life-style factors which, in accordance with current medical knowledge, made me at risk of developing breast cancer. Despite all of this however, like most of the women I knew, had heard or read about, the diagnosis came as a great shock accompanied by intense fear. Thus began the ride on what many in this situation have described as the breast cancer 'rollercoaster' of emotions (E. Adams, 2007).

From necessity, I engaged with a number of health professionals, each providing their specialist intervention in my diagnosis, treatment and care. Each brought to the medical encounter their experience and knowledge, and their own styles of engagement. In the course of this process, two particular encounters stand out and ultimately became the precursors to my research. The first was the difficulty my GP had in making eye contact with me while I awaited the consultation with him which would confirm or disconfirm the diagnosis of breast cancer. The second was a male breast surgeon's mirthful description of breast cancer as 'such a sexy disease'. From the position I was literally lying in at the time as his patient, it did not seem to be a particularly 'sexy' diagnosis. Small, and possibly trivial to others, these experiences weighed on me as a female patient and a psychologist. I began thinking about how this disease called breast cancer is socially constructed by how it is talked about today. What knowledge and understandings of it had dominated in the past and which of them continue to dominate and prevail? Who has that knowledge, how is it brought into play, and what is the effect on the speakers and listeners? Why, for example, had breast cancer been described in such a way, and why was an interaction with a familiar patient so difficult? With such proclaimed advancements in early detection and treatment for breast cancer, why did I feel so alone, powerless and afraid? What emotions was my GP covering or protecting himself or me from? And why did the breast surgeon's choice of words and stance strike me as unusual, powerful and personally upsetting? Being forced to engage with the medical world and its many different terrains to an extent that I had never had to before, highlighted for me issues of my sudden change of identity from 'well' to 'ill', and my emotional reactions to being in this position. I became very interested in talking to other women about their experiences, and, given the reactions of the two medical professionals and some other of my medical encounters, I was also keen to hear from the health professionals themselves about the impact on them of their engagement every working day with women with breast cancer.

## **Background to the Study**

Although women have reported that they often feel isolated and alone, experiences of breast cancer do not occur in isolation. Social historians tell us that our conceptions and constructions of events are greatly influenced by our past life and current social and cultural settings. Our reactions to breast cancer are affected by more than 3000 years of documented history of the disease, and by the way the female breast is viewed within our culture (Galgut, 2010). This call on history can be seen as a type of tactic or method used to legitimate medicine and medical discourse. History claims breast cancer in this way. The phenomenon of breast cancer has been variously described by women patients and cancer specialists as ‘mysterious’, ‘headstrong’ and as ‘making its own rules’ (Olson, 2002). The use of such words is both intriguing and concerning. Breast cancer, as a predominant disease in women has a long, and for me, interesting history, particularly in terms of the language used to describe it.

Despite its contemporary medical re-categorisation as a chronic rather than an acute disease, breast cancer continues to be one of the diseases most feared by women. This is because it is considered by the medical profession to be a serious disease and also because it is still not actually known how it arises (OECD, 2013). Most women respond to a diagnosis of breast cancer, or hearing of another’s diagnosis, with at least feelings of anxiety and some with dread (Galgut, 2010). Sometimes the cases that women hear and know about are those who struggled and who did survive, so there is potential for frightening and alarming discourses to continue to prevail about the disease. Like other developed Western countries, New Zealand has a relatively high incidence of breast cancer; but despite advances in detection and treatment it continues to be the most common cause of death from cancer among New Zealand women (Ministry of Health/NZHIS/BSA, 2009).

My initial search of the literature revealed that while there have been a large number of qualitative research enquiries using women’s pathographical narratives of their individual thoughts, feelings and actions about breast cancer, there have been much fewer investigations of the perspectives of health professionals involved in breast cancer care. In a culture where women’s attitudes, thoughts and reactions towards breast cancer are predominantly portrayed as having high emotional content, the likelihood that health professionals might experience emotion aligned to their work with female breasts seemed high (V. Adams, 2007; Balint, 1957; Galgut, 2010; Gwyn, 2002;). By including health professionals’ perspectives as well as those of women who had experienced

breast cancer, I intended to give voice to a group of speakers who previously had had little opportunity to talk about the impact on them of working in the breast cancer field. Given the potential size of the chosen topic, I decided to contain the boundaries of this study by looking only at interviewed women's accounts, and at health professionals' accounts of their experiences with breast cancer within my chosen research setting of the medical encounter.

### **The Philosophical Approach and Aims of the Study**

The epistemological position for this study needed to account for the diverse ways of thinking about breast cancer and the subjectivities that each might produce. I required a philosophical approach by which I could identify the different ways that breast cancer is talked about (discoursed) and the deployment of these different forms of knowledge of breast cancer which might be used to assert power and produce different power relations, subject positions and identities. I was drawn to the post-structuralist theory developed in the 1970s writings of French philosopher Michel Foucault (1926-1984), in particular his concept of discourse and his notion that discourse systematically constructs the object, event or phenomenon of which it speaks (Foucault, 1972). His method of identifying and analysing multiplicities of possible discourses and constructions of knowledge seemed particularly apt for my study because of its ability to challenge existing political, institutional and cultural 'technologies of truth', particularly in medicine (Gordon, 1980). I was excited by this relatively new approach to qualitative research because of its capacity to uncover not only what is spoken openly, but what is also, for whatever reasons, left unsaid. Post-structuralism is then the theoretical perspective within which this study is located, and the term 'discourse' is central. Foucauldian discourse analysis is both the methodology and the research method used to shape the steps of data collection and analysis.

The strength of Foucauldian discourse analysis as a research methodology and method is its ability to dig beneath the surface and uncover social constructions of experiences which explain why individuals behave in the ways that they do. This study brings an application of the methodology of Foucauldian discourse analysis specifically to the topic of breast cancer. A review of the breast cancer literature confirms that this has not often been attempted before, although those few key pioneering studies gave me inspiration for my own. For example, Katrina Breaden's (2008) study of breast cancer in young women; Jean Lugton's (2002) study of social support of breast cancer patients; Deborah Lupton's (1994a) analysis of breast cancer discourses in the Australian press;

Margaret O'Connor's (2006) enthusiasm for discourse analysis in research on palliative care; Sue Wilkinson's (2000) investigation of feminist research traditions and health psychology with regard to breast cancer; and similarly Sue Wilkinson and Celia Kitzinger's (2000) focus on women talking about causes of the disease. All convinced me that Foucauldian discourse analysis is a very powerful tool by which to explore further how breast cancer is constructed within individual accounts.

When considering how best to interpret my data, I found that within a positivist paradigm, individuals' accounts of having breast cancer, or working within this specialist medical area, are generally categorised and transformed into numbers. The speakers themselves become invisible during this process and their accounts become academic. The medical research community does not as a rule hold the use of personal experiences and accounts in studies in high regard (Breaden, 2008). These stories are considered to be lacking in scientific objectivity and rationality. In contrast, studies conducted within an interpretive paradigm focus on individual accounts. The personal accounts of both women and health professionals make them available to all, thereby countering the tendency of the scientific method to silence speakers, or rendering them voiceless and powerless (Foucault, 1982a). Rather than viewing these subjective experiences as questionable, accounts of experiences are valuable resources from which researchers can draw (Banister et al., 1994).

The overall aim of this study is to investigate how breast cancer is constructed by the discourses deployed by women and by health professionals in the second decade of the 21<sup>st</sup> century in New Zealand. A second aim is to further analyse the discourses of the study participants in order to identify the subject positions taken up by both women patients and health professionals, and how these might create subjectivities. Foucauldian discourse analysts conceptualise language as constitutive of experience rather than representational or reflective. The over-arching hope for my analysis is that it will provide valuable information about the impact of breast cancer experience on both women patients and health professionals. My thesis or main argument is that the interplay of the dominant discourses by which women and health professionals construct breast cancer generates significant emotional impact on both parties. Such findings from this post-structural analysis might lead to a deeper understanding of the strengths and difficulties in current breast cancer practice, and provide some indicators of how such factors may be enhanced or addressed within the medical encounter.

This study does not claim in any way to be exhaustive, and even if it did, such an objective would be impossible to achieve. As cautioned by Silverman (2006), it is in fact unwise to over-emphasise or promote a specific method of analysis in a field where personal factors, sensitivity and motivation play such an essential part. Rather, this study offers an analysis of particular dominant discourses and discursive practices relating to breast cancer. Certain themes have not been touched on or included (such as issues of ethnicity) because these are specialties in themselves which I leave to more competent researchers. The following presents an outline of what each chapter contains.

## **Study Outline**

Overall, the study explores the complex nature of the dominant discourses which construct breast cancer within the four stages of its discovery, diagnosis, treatment and recovery for women patients and for health professionals in the first decade of 21<sup>st</sup> century New Zealand. The framework of post-structuralism drives this research, especially the concepts of discourse and subjectivity. As the following chapters indicate, there is no single 'truth' concerning breast cancer – either for women or for health professionals.

In Chapter Two I introduce my key theorist, Michel Foucault and my rationale for selecting the main Foucauldian concepts which underpin this study. The chapter begins with a description of post-structuralism, the basic assumptions on which its practices generally operate, and its value for the purposes of my study as the epistemology in which I locate Foucault. The main concept derived from Foucault's work and which shapes the steps of my data collection and analysis, is discourse. The Foucauldian concept of discourse is defined and discussed in relation to the study, as are its links to power, knowledge and subjectivity. Application of Foucault's concepts of archaeology, genealogy, and history as methodological tools to breast cancer will inform an analysis of the associated technologies of disciplines and power.

Chapter Three is an explanation of how the research methodology shapes the research method – that is, from discourse analysis to the actual steps involved in undertaking the study. I explain first my choice of a qualitative rather than a quantitative research approach. The techniques used to select and recruit the 37 participants are described and discussed. This is followed by an explanation for my focus on 'text' as the method of study, and for interviewing as the method of collecting data. An explanation of the process for recording and transcribing the data is then provided, as are the procedures

used to ensure the adherence to ethical principles such as informed consent, confidentiality, storage of information and minimisation of risk. Foucault's depictions of power and positioning in social interactions, such as even those of the qualitative interviewer-interviewee, necessitated the implementation of mechanisms for self-reflection (reflexivity) by me as the researcher. Throughout the conducting of this research I also needed a process by which I could be vigilant to my own biases as a psychologist and as a woman who had had breast cancer, and I describe this process at the end of the chapter.

In Chapters Four and Five I present archaeological and genealogical analyses of the literature in relation to breast cancer and women and health professionals. The analyses explore the historical, social and cultural contexts within which various discourses and their constructions of breast cancer are articulated. A genealogical analysis of the literature relating to breast cancer also involves the specific apparatus and technologies within the institutions of medicine (hospitals and Breast Care Clinics), public health (campaigns and screenings), and the socio-cultural discourses which prevail at a given time, and which, I suggest, continue to predominate. Foucault is actually very historically specific, seeing forms of power/knowledge as always rooted in particular contexts and histories. Given breast cancer's very long history, there is ample scope to trace its past and current constructions and discourses from the many states of knowledge about it, and the important role played by knowledge in the ways that we 'invent ourselves' (Rose, 1996a) in diverse subjectivities. Because breast cancer is dominantly constructed by medicine and thus commonly thought of in Western society as a 'disease', the focus in Chapter Four is on the literature pertaining to the medical discursive field of breast cancer. Chapter Five contains a review of the literature with reference to the gender discourse and the effects of breast cancer as a 'disease of women' on women, and on the professionals who care for them. The reviews reveal the multiple and overlapping discourses that compete with one another as identified in the historical, medical, social and cultural breast cancer literature. Foucault describes his work on a number of occasions as the history or diagnosis of the present, or as the analysis of 'what today is' (O'Farrell, 2005). The empirical literary backdrops presented in Chapter Four and Chapter Five are critical to my study's aim of identifying and analysing the dominant discursive constructions of current explanations, imagery, and practices concerning breast cancer. The Foucauldian question applied throughout his methodology of discourse analysis and applied in this study is 'how is today the same or

different from yesterday' (O'Farrell, 2005) for each of the speakers within the medical encounter?

Chapter Six begins my presentation of the findings of the study. I have chosen to organise these findings by describing them from the women's and the health professionals' points of view at each 'stage' of the breast cancer experience, namely: discovery, diagnosis, treatment, recovery, and use these stages as chapter titles. I analyse my findings in this way because of the different subjectivities for women and health professionals related to the woman's passage through the health system once breast symptoms had been discovered. In this chapter I explore and analyse the women's texts regarding the discovery of breast symptoms, the discourses that they articulated and the subject positions taken up. My analysis focuses on the setting and the way in which the symptoms were discovered. The impact of these factors on the women's psychological and social reactions and behaviours are revealed. I argue that the influence of commonly-held medical and social knowledge about breast cancer impacts significantly on women when symptoms are discovered.

Chapter Seven contains an analysis of both women's and health professionals' texts regarding diagnosis. It is at this stage that the women first engage with the medical system and its diagnostic 'gaze'. This generally involves the women's interactions, firstly and usually with their GPs, then referral on to unfamiliar specialists and by necessity engagement with oncology's technology of mammography or thermal imaging and biopsy. Various subject positions are brought into being by the intersection of medical discourse with gendered discourse.

In Chapter Eight I identify and analyse the discourses and discursive practices in relation to the treatment of breast cancer. There are three main medically-accepted types of treatment – surgery, radiotherapy and adjuvant chemotherapy with pharmaceutical intervention often following these. The findings in this chapter emphasise that health professionals too, are made subjects of the medical discourse in the ways that they represent themselves and the women with breast cancer requiring treatment. Analysis of the women's and professionals' texts highlighted the unstable and contestable nature of the power relations of resistance between women and health professionals, revealed through their articulation of fear and anxiety during treatment.

In Chapter Nine I identify the dominant discourses by which women and health professionals construct recovery from breast cancer. I analyse the women's accounts of

being in a position of ‘looking back’ on the experience of having had breast cancer, and the various subject positions and discursive practices deployed by them during this time. I argue in this chapter that the on-going impact of medical and public health techniques of power means that the women live constantly, and will continue to live with levels of threat to their physical health and emotional well-being as the result of having had breast cancer.

In the final chapter, Chapter Ten, I answer the two main questions posed in this research, thereby providing a summary of findings. These two questions related: (1) to the identification of the dominant discourses deployed by the women and health professional participants in their constructions of breast cancer, and (2) to the effect of the interplay of these discourses on the subject positions taken up with their inherent subjectivities and identities, discursive practices and behaviours. From the analysis of the interview data, I firstly confirm that there were two predominant discourses by which the women participants and the health professionals constructed breast cancer, and their experiences of it. These were the medical discourse, and the gender discourse. This chapter reflects the centrality of the health professional - patient relationship or the medical encounter as the main setting in which these discourses were deployed and the respective discursive technologies of power played out. My thesis is that the interplay of the medical and gender discourses at all four stages of the breast cancer experience – discovery of symptoms, diagnosis, treatment and recovery, produced the fearful woman subject, and the anxious health professional. The last part of this final chapter contains a discussion of the theoretical significance of the findings of this study together with its limitations, suggestions for areas of further research, and implications of the study for education and practice.

I began what I thought was going to be a relatively straight-forward descriptive study of women’s and health professionals’ accounts of breast cancer. Over the last eight years I have made the difficult but liberating move to a post-structuralist Foucauldian-based discourse analysis of these accounts - of the constructions, practices and subjectivities of the women and health professionals involved. It is the results of this methodological move that I present in this thesis.

In summary, in this introductory chapter I have presented the topic of my study and the background to its choice. I posed the main research questions related to the topic, and described the philosophical underpinnings and research method I used in order to best



answer these questions. The content of each chapter in the study is outlined, and the main findings are discussed together with the implications of the findings.

In the following chapter I locate Foucault within post-structuralism, and identify and describe the concepts from his work upon which I have drawn and have employed in this study.

## **CHAPTER TWO: PHILOSOPHICAL UNDERPINNINGS**

### **Introduction**

I begin this chapter by describing more fully the theoretical epistemology of post-structuralism on which this thesis draws, and the post-structural concepts essential to the study. I then describe and the philosophical approaches of French philosopher and historian Michel Foucault, and the significant concepts and approaches to discourse and discourse analysis developed by him that shape my methodological approach and research methods.

Foucault changed his mind many times about the role played by philosophy and the philosopher or intellectual. The tradition of intellectual history tended to focus on the well-formed, clear ideas of philosophers, writers and other thinkers, and the vague thoughts and perceptions of the everyday person were often excluded from study (Whisnant, 2012). Foucault frequently emphasised that philosophy should deal with the question of what was/is happening right now. He suggested in several of his works that by focussing on the continuity of ideas, there was a danger of missing the possibility of massive discontinuities or ruptures which had come before (Foucault, 1970). He also defined the task of philosophy as not reflecting on what is true and what is false, but rather a consideration of our relations to ‘truth’ and how we should conduct ourselves (O’Farrell, 2005).

Foucault’s contributions to the social sciences and humanities over the past two decades have been profound, particularly in studies of health and medicine (Petersen & Bunton, 1997; Jones & Porter, 1994). For example, his ideas and methods have been increasingly used in health care fields, with classical illustrative studies in medical sociology (Lupton, 2012; Osborne, 1997; Turner, 1996), psychology (Rose & Abi-Rached, 2012), dentistry, (Nettleton, 1994) and nursing (Cheek, 2000; Gastaldo & Holmes, 1999). His concepts and methodology have encouraged new approaches to old problems and have opened up new lines of enquiry because they are well suited for analysing struggles over meaning and power conflicts (Whisnant, 2012). While Foucault’s approaches have been used to very powerful effect by practitioners in medicine (Armstrong, 1997; Little, et al., 1999), his ideas have not often been applied specifically to the topic of breast cancer (Breaden, 2008; McCarthy, 2005). My aim in this chapter is to demonstrate the particular relevance of Foucault’s approaches when

applied to the analysis of women's and health professionals' discursive constructions of breast cancer.

### **The Epistemology of Post-structuralism**

In this section I describe post-structuralism as the epistemology in which I locate Foucault, and provide an explanation of its growth as an accepted school of thought and its influence on the philosophies and theories of discourse and discourse analysis. An extension of the ideology of postmodernism (Grbich, 1999; Ward, 1997), post-structuralism is defined in relation to the term from which it is derived, namely 'structuralism' (Crotty, 1998). It emerged as a reaction against the claims of the scientific rigour, objectivity and universal validity of 1960s French structuralism. With its early roots in the 18<sup>th</sup> century movement of Enlightenment and in the birth of the human sciences, post-structuralism stresses the importance of reason and the critical reappraisal of existing ideas and social institutions (Foucault, 1973; Sarup, 1993).

The epistemology of post-structuralism has come to be loosely defined as an eclectic school of thought, and one which significantly influenced literary criticism and cultural theory in the 1970s and 1980s. Such theories became known as post-structural - the prefix 'post' referring to the countermovement of many contributors such as Jacques Derrida, Julia Kristeva and Foucault who were highly critical of structuralism's claim to comprehensive and objective exploration of political, institutional and cultural structures (Jones & Porter, 1994). Post-structuralism denies the objectivity of linguistic and cultural codes, language, and categories of conceptualisation. Rather, it emphasises the instability of meanings and categories, and the inability of any universal system of rules of language to explain reality. The result is a radically non-hierarchical approach to text which has a multiplicity of indeterminate meanings (Harrison, 2006). Post-structuralism's key features then are an acceptance of fragmentation and discontinuity of meaning, a suspicion of grand narratives and science, and a rejection of history and the notion of progress (Muir Gray, 1999; Sarup, 1993). Meanings and intellectual categories are viewed as shifting and unstable because there are no facts, only varied interpretations, with language being considered as unstable and fluid (Foucault, 2003; Ward, 1997).

Foucault continually used the principles of discontinuity, break and difference in his analyses to challenge philosophical notions of unchanging truths in history and humanistic thinking. For Foucault, discontinuity meant that a culture sometimes ceases

to think about (construct) an object or subject as it had been doing up to that point, and begins to construct it in a new way (Foucault, 1970). The core of post-structuralism is its focus on the constructive power of language. As Belsey (2002) writes, “after food and shelter ... language and its symbolic analogues exercise the most crucial determinations in our social relations, our thought processes, and our understanding of who and what we are” (p. 60). Conversely, while a post-structuralist approach constructs objects such as a breast tumour cancer, and subjects such as women with breast cancer and health professionals through discourse (Breaden, 2008) it also has a deconstructive process by which to explore these constructions. This central post-structuralist notion of deconstruction claims that the meanings and concepts of language constantly shift in relation to a myriad of variables because the culture and society of the listener/hearer share equal parts with those of the speaker in the interpretation of a piece.

The theory of post-structuralism is important for my study because it goes some way to accounting for why people use the rules of a language system in one way and not in others, at some times and not at others, and why some words have many meanings and how meanings change over time (Foucault, 2003; Weedon, 1987). However, post-structuralism is difficult to define or to sum up because by its very nature it rejects definitions that claim to have discovered ‘truths’ or facts about the world, such as the ‘truths’ and ‘facts’ about breast cancer. Post-structuralists, such as Foucault, believe in the limitless instability and incoherence of language, and maintain that the only way to properly understand these multiple meanings is to deconstruct the assumptions and knowledge systems which produce the illusion of any singular meaning (Caputo, 1997). Careful deconstruction of a given communication will reveal contradictions by the speaker, and these, together with inconsistencies and disconnections in the interpretations and criticisms of the hearer, will lead to different (possibly unique) meanings of what has been said (Foucault, 1981). Deconstruction then is a critical concept in the methodology of discourse analysis applied in my study.

While Foucault’s post-structural stance was helpful in challenging my thinking about structure, change and continuity, one of the challenges of his philosophy is that his concepts do not fit readily into any particular discipline or theory. As a result it was helpful for me to think of him as the founder of his own ‘school of thought’, (O’Farrell, 2005). The general Foucauldian approach has been described by some as ‘the Foucauldian tool-box’ (McLaren, 2009; Patton, 1979; Osborne, 1991), or his writings as

a “box of tools” (Foucault, 1974, p. 523) which are essentially a set of strategies he offered for understanding how discourses construct subjects and objects of knowledge, experiences and identities. Selecting tools means that the researcher uses only those strategies of analysis which fit his/her particular task, rather than forcing scientific evidence through a scientific theory, and which as a result has already pre-destined the research findings (Osborne, 1991; Turner, 1997). The following is a discussion of the key concepts and methodological tools developed by Foucault which I apply in this study: discourse, discursive object, subject position, subjectivity/identity, discursive practice, and technology of power.

## **Discourse**

Discourse is central to Foucault’s work, but researchers using discourse analysis methodology and methods can find his vague definitions of what he meant by the word problematic (Osborne, 1991; O’Farrell, 2005; Turner, 1997). Normally the term discourse is used as a linguistic concept, simply meaning passages of connected writing or speech (Cameron, 2001). Foucault, however, regarded discourses as “practices which systematically form the objects of which they speak” (Foucault, 1972, p. 49). By this Foucault meant that discourse constructs objects, and interprets events and phenomena in a particular way (Kendall & Wickham, 1999). Discourses are performances, activities or events, or ways of doing things (McNay, 1994). At its most basic level Foucault described discourse as “a certain way of speaking” (Foucault, 1972, p. 193), but he also used the term to refer to material verbal traces left by history. Thus, discourse engenders a regular effect – a systematised way of thinking about the same thing at a particular historical moment (Mills, 1997). Foucault argued that when we use language to explain, communicate or retell an experience, it is an experience that is located in a particular history of context (Allen & Hardin, 2001; Mills, 1997). For example, when women and health professionals talk about their experience of breast cancer they are not speaking of a private or individual experience (although their thoughts are individual to them, and often private), but rather of “public understandings that are given voice through this individual experience” (Hardin, 2003, p. 538). Personal experience is dependent on and located within a wider framework of public understandings.

Through careful examination of discourses we are able to trace their role in the wider social processes of legitimatising power, emphasising the construction of current truths, maintaining these truths, and establishing what power relations they carry with them. Foucault’s discursive analyses concentrate on the criteria according to which specific

views are considered legitimate contributions and in which individuals are allowed to participate or otherwise, or more specifically, who gets to participate and contribute and who is excluded. This question of inclusion and exclusion from discourses is the central theme of much of his work (Foucault, 1972).

Foucault's notion of discourse thus allows us to think about a wide variety of talk, text and practices from different countries, historical periods, disciplines and genres. For example, discourses on breast cancer might include talk and texts by health professionals who work with breast cancer, narratives and biographies of breast cancer patients, popular media talk and text about breast cancer, writings by breast cancer researchers, as well as writings about breast cancer from other disciplines (Lipmann, 2011). I have restricted my study to the discourses deployed by women who have experienced breast cancer, and by health professionals who care for such women. Foucault's methodological approach to discourse is very relevant to my study because it provides an understanding of the social boundaries which define what can be said about breast cancer, or, as post-structuralist feminist scholar Judith Butler (1997) puts it, "what the limits of acceptable speech are about ..." breast cancer, or what are its current "truths" (p. 34).

Foucault and other post-structuralists also assume that any given society is infused with many competing discourses. Discourses exist and operate alongside others, and compete for dominance and power. Foucault's notion of discourse does not focus specifically on power struggles between different classes and genders, or between the state and its subjects. Instead, it suggests that power is diffuse, and power conflicts can happen at different sites and levels (Gordon, 1980). Foucauldian discourse assumes that ideas structure social spaces and can therefore play a significant role in historical change (Dean, 1994). Discourse analysis focusses on the small shifts and differences in how ideas are expressed in language. Within discourse and critical theories, language can be broken into different "[bodies] or [corpuses] of statements and utterances governed by rules and conventions of which the user is largely unconscious" (Macey, 2000, p. 100). Analysis reveals the very specific patterns of language-use which identify characteristics of the speaker. These include the culture of which the speaker is part, the network of social institutions to which the speaker belongs, basic assumptions that the speaker holds, and the speaker's implied relationship to the other people around him or her. For example, discourse analysis allows the identification of the differences between professions or occupations, or players and speakers within specific social interactions.

Medical discourse, for example, gives doctors, within specific locations such as clinics, hospitals or surgeries, the right or authority to speak on medical matters, thereby placing them in a position of power over their patients (Foucault, 1972). Discourse then, according to Foucault, is the regulations of language that shape our lives, and discourse analysis looks for patterns of language such as the sets of rules that govern a specific style of language. As Foucault put it, “whenever one can describe ... between objects, types of statement, concepts, thematic choices ... we are dealing with a “discursive formation” (Foucault, 1972, p. 38). There is a fundamental methodological premise in Foucault’s work that discourse, as knowledge and truth claim, plays a significant role in constructing what is ‘real’ for each of us. Yet, despite his highlighting of the connection between discourse, power and knowledge, Foucault never articulated any actual methods for analysing discourses within empirical data (Hindess, 1996). Instead he developed rules for locating discursive formations and identifying discourses (Foucault, 1981).

### **Rules of Formation**

Foucault developed three ‘rules of formation’ of statements. Discourse analysis involves the identification of the rules and conditions that a discourse is subject to. The first of these rules is what Foucault (1972) calls ‘surfaces of emergence’. Genealogical historical surfaces of emergence allow the emergence and identification of a ‘discursive object’ or ‘subject’.

### **Discursive Object**

A discursive object or subject is constructed by language, given a name and a status, and exists within certain social and historical contexts. Surfaces of emergence are sites where individuals are differentiated. Having a lump in the breast brings women into the domain of medicine/oncology (Armstrong, 1995; Breaden, 2008).

The second Foucauldian rule of formation of statements is ‘authorities of delimitation’. By this Foucault (1972), meant groups or bodies that have the power to give a name or description to the object, event or phenomenon. This is particularly seen in the medical profession, which has the power to label, delimit and determine the boundaries of the discursive object of a lump in the female breast, or the subject of medical patient.

‘Grids of specification’ was Foucault’s term for the classificatory systems or divisions between discursive objects. Discourse analysis involves the identification of the terms

and concepts routinely used to differentiate one discursive object or subject from another. Foucault developed the notion of using the idea of a grid by which the conditions and circumstances that allow a discourse to exist and to be seen in a particular way could be recognised. Grids of specification are within a discourse, such as the grades of a cancer. The differentiation between, say, Grade 1 and Grade 2 cancer is within, and indeed created by, medical discourse.

### **Subject Position**

According to Foucault (1972), the rules of language determine the name, position and role of the speaker – the subject position. The positioning of the speaker and the site where a discursive statement can be made are determined by the speaker him or herself or by others in authority (Dreyfus & Rabinow, 1982). Positioning is the discursive process whereby individuals are observably and subjectively located in conversations as coherent or incoherent participants in jointly-produced story lines. Because the speaker's subject position is determined by his or her relationship to the discursive object or subject, only specific people can legitimately deploy a discourse or carry out a discursive practice, action or behaviour. The subject position shapes the speaker's roles and identities (subjectivities) within the discourse. For example, within the medical discourse the roles of GP or specialist, or woman patient, are shaped by their respective relationships to the discursive object - the breast lump. The diagnosis of the breast lump is a point of social interaction and power relationship which is determined by the discursive rules for constituting 'true' knowledge. The doctor, who holds knowledge of medical science, is the legitimised speaker of the medical discourse, and the woman is placed in the position of its docile subject (Foucault, 1977).

Davies and Harré (1990) and Harré and van Langenhove (1999) also contend that there can be interactive positioning in which what one person says positions another, and reflexive positioning in which one positions oneself. This underpins their notion of inter-active subjectivity. However, they warn that it would be a mistake to assume that, in either case, positioning is necessarily intentional. An individual lives his or her life in terms of an on-going produced self, whoever might be responsible for its production.

Discourses allow subject positions from which a person views the world from particular perspectives, but which can be contradictory. For example, there are a number of conflicting or alternative positions which could be taken up by a woman diagnosed with breast cancer. It can be seen that a subject position is different from a role, which is a



prescribed way of acting and behaving (Willig, 2001). Davies and Harré (1990) suggest rather that with subject positioning the focus is on the way in which speakers and hearers are constituted in certain ways, and “yet at the same time is a resource through which speakers and hearers can negotiate new positions” (p. 62).

Although contradictory, subject positions can exist between numbers of individuals, they can also co-exist within the same individual (Davies & Harré, 1990).

Foucault’s (1970) stance was that in speaking and acting from a position, people are bringing to the particular situation their history as a subjective being, that is, the history of one who has been in multiple positions and engaged in different forms of discourse at different times and for different reasons. Thus it becomes possible to explore how each speaker constructs him or herself, and how he or she is constructed by discourse, and what positions each take up. Such analyses emphasise the dynamic nature of subject positioning, seen particularly through the Foucauldian constructions of choice and agency (discursive practices), and control and power (discursive technologies of power) (Foucault, 1982a).

### **Discursive Practices**

Foucault (1972) described discursive practices as the actions subjects take as the result of the subjectivities or identities assumed through their relationship with, or positioning to the discursive object. This encompasses not just what subjects say, but also their behaviours. Discourse is the consequence or outcome of human thought and practice (Allen & Hardin, 2001), that is, “embodied in technical processes, in institutions, in patterns for general behaviour ...” (Foucault, 1977, p. 200). Discursive practices thus express discourses and are themselves discursive events.

In order to identify and analyse discourses and their discursive objects, subject positions, practices and power within them, Foucault (1977) developed a number of methodological guidelines by which researchers could conduct their own forms of discourse analysis to meet their particular goals.

### **Foucault’s Theoretical ‘Tool-Box’**

There is a lack of clear precepts for conducting discourse analysis in Foucault’s work. Instead he wrote books, projects or ‘tool-boxes’ (Foucault, 1977) containing methods of data extraction, on which he gives discourse analytic researchers freedom to draw, depending on their own thematic research schema or theoretical perspectives (McLaren,

2009; Patton, 2002, Osborne, 1991). The first of these projects Foucault termed 'the archaeology' of knowledge production (Foucault, 1972).

### **The Archaeology of Knowledge**

Foucault developed his own notion of archaeology as a tool for discourse analysis by which to find, or metaphorically excavate knowledge and write history. This archaeology has become an accepted Foucauldian term designating the collection of all material traces left behind by a particular historical period and culture. In his early work *The Order of Things: An Archaeology of the Human Sciences* (1970), Foucault was largely concerned with what made certain knowledge ('knowledges'- *les savoirs*) possible and why they suddenly changed their form and content. The archaeology was the first significant 'ordering tool' he developed in some detail by which he was able to investigate individual events and discover radical transformations and discontinuities in the conditions for human knowledge. In describing the archaeology later in *The Archaeology of Knowledge* (1972), Foucault said that the analysis of the statement as it occurs in the system of statements ('archive') was his main concern, and was about examining the discursive traces left by the past in order to write a 'history of the present' (Foucault, 1989).

The Foucauldian archaeology helps us to explore the networks of what is said, and what can be seen in a set of social arrangements - which open up statements and other visibilities (Davidson, 1996; Howarth, 2002). The overall purpose of Foucault's form of archaeology was to excavate the socio-historical contexts in which truth and knowledge are produced by disciplines (such as pedagogy, psychology, sociology, medicine and the law). In other words, Foucault's archaeology was about looking at history as a way of understanding the processes that have led to what we are today (Calvert-Minor, 2010). The archaeology aims to understand the conditions that are held in a given time and place for producing disciplinary knowledge about a problem (such as breast cancer), and which are seen to justify what is said to be 'true' about that problem. That is, its aim is not to uncover the ultimate 'truth' about the problem (McCarthy, 2005). The archaeology does not champion, for example, the unquestioned 'truth' upon which all breast cancer treatment is based, that a breast tumour is abnormal. Instead, it acknowledges that this is held true by oncologists and unearths the conditions that have allowed them to construct this 'truth' (Barrett, 1991).

Foucault's archaeological approach also demonstrated that the development of disciplinary truth and knowledge does not develop in a linear way. In other words, knowledge does not accumulate on a smooth trajectory over time towards a truth that provides the ultimate answer to a problem. For example, leading up to the modern understanding of breast cancer, the humoral theory of the cause of the disease did not contribute seamlessly to tissue theory, which in turn did not contribute smoothly to the later theory of the cellular nature of tumours, and which over time has turned back to a re-focussing on the bodily network of vessels conveying fluids. Each theory was revolutionary in its time, seeming to appear out of nowhere, and rife with intra- and inter-disciplinary politics (Olson, 2002). Thus, Foucault argued that the present state of disciplinary knowledge is an inevitable outcome of what has gone before. Present understandings have been arrived at through the contingent interplay of historical events, and because new ways of speaking the truth develop as present knowledge rather than as true knowledge (Foucault, 1981). Such understanding and truths led to the development of different disciplines so that today a body with breast cancer is constructed medically in terms of genes, cells, organs and tissues, and treatments and therapies are targeted at them accordingly. Likewise, a mind analysed for psychological distress remains a psychological object constructed by psychological discourse (Lupton, 1997), and a woman is a gendered subject constructed by sociological gendered discourse (Crawley et al., 2008; O'Brien, 2009). Foucault's methodology of the archaeology exhumes and examines successive transformations of those favoured and out-of-favour ways of conceiving things that appear at a given time, noting where they overlap, and where they suddenly reappear as truthful discourse to "continuously produce re-shapings of their own history" (Foucault, 1989, p.15).

Foucault's project of archaeology was a new kind of re-shaping of history and historical analysis that moved from the continuous and gradual development of thought in traditional history. By analysing individual events, archaeology is able to discover radical transformations and discontinuities in the conditions for human knowledge. Its focus on discontinuities rather than continuities pin-points breaks and ruptures in thought and demonstrates that there is no such unifying principle for the whole of history, or of 'man'. The feature that best distinguishes archaeology from other forms of history (total or general), then, is its focus on the specificity of statements within particular forms of discourse.

## **Genealogy**

‘Genealogy’ was the term Foucault (1989) used to describe the expansion of his historical approach that augments the assumptions and tools of the archaeology with a particular emphasis on knowledge and power (Hardy, 2010; Hook, 2003; Prado, 2000). The differences between Foucault’s archaeology and genealogy are generally difficult to discern because the tools he used to practise both methods are essentially the same. While archaeology focusses on the organisation of manageable forms of knowledge, and addresses the levels at which differences and similarities are determined, genealogy looks at levels where the grounds of the true and the false come to be distinguished through mechanisms of power and power relations. Genealogy takes archaeology further by mapping the systems of disciplinary power within institutions and the discipline’s relationship with other systems of power (Kendall & Wickham, 1999). The strongest characterising feature of disciplinary power is knowledge (Hook, 2003), or as Foucault (1980) coupled the terms, power/knowledge. Foucault hereby asserted the complex interface of these two terms, underlining the mutually reinforcing nature of their relationship, and their inseparability.

Foucault (1982a) also suggested that disciplinary power has a deliberate ambiguity because it not only objectifies individuals, but also subjectifies them (Rose, 1996a). Disciplinary power produces subjects who are subject to control and which are also controlled by their own identity through self-knowledge or conscience (Davidson, 1996; Hook, 2003). Foucault’s genealogy therefore, particularly focussed upon the effects of disciplinary power on the individual body, examining the ways that people are made subject to it and the subjectivities and identities they assume in order to reject or overcome that subjection. Foucault argued that the ultimate aim of genealogy is to make us see beyond the ways we are currently controlled by disciplinary discourse and to choose a power system that better suits our need (Carabine, 2001; Hook, 2003).

Foucault’s genealogical analysis of discourse was informed by the *dispositif*. He generally used this term to indicate the various institutional, physical and administrative mechanisms and knowledge structures (apparatus) which are deployed to enhance and maintain the exercise of power within the social body (Deleuze, 1992). The *dispositif* maps the practices, discourses, institutions, architectural arrangements, laws, philosophy and morality of a discipline. It examines all of those things that support the power base of the disciplinary world-view. Using the *dispositif*, the genealogy, like the archaeology, unearths what the discipline, mechanisms and knowledge structures once were,

including the more unpleasant and hidden origins, and what they have become. This, according to Foucault, is achieved through discourses which ensure 'docile bodies'. "The body is directly involved in a political field; power relations have an immediate hold upon it; they invest it, mark it, train it, torture it, force it to carry out tasks, to perform ceremonies, to emit signs" (Foucault, 1977, p. 25). As Rose puts it in an introduction to Kendall and Wickham's (1999) book on using Foucault's methods, Foucault's genealogy concerns itself with "disreputable origins and unpalatable functions" (p. 29). Genealogy is therefore a methodological device which points out things about origins and functions of knowledge that certain related parties would rather remain hidden.

### **History of the Present**

Foucault's work was imbued with an attention to history, but not in the traditional sense of the word. Rather, his attention was on the continuities and discontinuities between 'epistemes', or the knowledge systems which primarily inform the thinking during certain periods of history. A different episteme was said by Foucault to dominate each epistemological age and the social context in which certain knowledge and practices emerge as permissible or are changed (Pinkus, 1996). His simultaneous examination of particular knowledge and practices within a specific historical period revealed differences and similarities between the past and the present. This notion of history was critical to Foucault's work, or more accurately his application of the theory of historicism – that is, that social and cultural phenomena (such as the experience of breast cancer) - are determined by history. Foucault's (1970) approach to historicism was to challenge that all 'history' is history seen only from the perspective of the traditional historian. "... All knowledge is rooted in a life, a society, and a language that have a history; and it is in that very history that knowledge finds the element enabling it to communicate with other forms of life"( pp. 372-373).

Foucault's (1989) view of history was a commentary of what he called the 'history of the present'. Rejection of the unified subject in terms of its dispersion throughout various manners of discourse from Foucault's genealogical approach allowed for what he saw as the 'emergence of man'. Man simultaneously constituted himself as the transcendental foundation of knowledge and as the primary empirical object of the science. For Foucault, we are both the subjects engaged in the science and the object of the science, but when those things that extend from man are seen as having their own internal histories, man begins to lose the foundation of the history (Canning, 1994).

Instead he gives himself his own history (Foucault, 1970). Foucault argued that the historian should not seek to interpret what an historical issue might mean in terms of the period being studied, nor in terms of the present period – a process he believed perpetuated an on-going cycle of ‘interpreting interpretations’ (Foucault, 1970). Rather as a beginning, Foucault recommended that the historian of the present examines the chosen discourse in places where chronological breaks are easily discernible (Foucault, 1972). These breaks are useful indicators of a change, for example, in the breast cancer world-view, of a different order of things that organises what was or is deemed valid knowledge about breast cancer at a particular time and what was or is not (Danaher et al., 2000). Signs that indicate such breaks include the establishment of new modes of exclusion and confinement within institutions, and the ability to trace certain present-day notions back to certain individuals and other primary concepts. In relation to cancer, the establishment of dedicated cancer hospitals in the late 18<sup>th</sup> century might be an example of such a significant turning point. The application of Foucault’s notion of history then, is not so much in seeking to find out how the present emerged from the past, but rather to use history as a way of ‘diagnosing’ the present (Rose, 1999) by examining carefully those things which are problematic, thereby disturbing the taken-for-granted from our past (Kendall & Wickham, 1999).

Foucault (2001a) called this ‘problematization’ - the history of a problem, or the point at which discursive objects and practices are made problematic and therefore visible and knowable (Deacon, 2000; Fosket, 2000). It is Foucault’s particular method of analysis, which he calls “thinking problematically” (Foucault, 1977, p. 185), “...the analysis of the way an unproblematic field of experience or set of practices which were accepted without question ... becomes a problem, raises discussion and debate, incites new reactions, and induces a crisis in the previously silent behaviour, habits, practices and institutions” (Foucault, 2001, p. 74).

Another important feature of Foucault’s approach to history was his objective stance. He believed that alternatives to modern thinking about (i.e. not solving) problematic phenomena (such as breast cancer) are only achieved by detaching from them. His aim was to distance himself from a problem, a problem like breast cancer, that a culture or a society recognises must be managed, and to reflect upon it in terms of the problems it poses when it required management and government (Rabinow, 2001; Fosket, 2000). This approach deliberates on what was actually done about the problem, on the conditions under which individuals and societies come to act in different ways around

that problem, on the effect this conduct has within a given social context, and the social system that such actions serve (McCarthy, 2005). A significant consequence of this type of objective historical exploration is that it can open up spaces for other ways of thinking about the problem (Danaher et al., 2000). As Foucault demonstrated, the way that is most obvious at any given time, is not necessarily the only way to think about or deal with something. His approach to history then, was to select an object or phenomenon and to analyse why it was constructed as a problem at that given time, and by whom, rather than concentrating on an historical period for investigation. This is not to discern the ultimately unattainable truth of an object such as breast cancer, but to undermine the obviousness of how we presently see it (Foucault, 1989; Osborne, 1991). Foucault's historical methods then, were essentially about problematisation (Foucault, 1998), with an emphasis on *how* something came to be viewed as a problem, rather than *why*. One of the goals of my study is to explore how breast cancer is constructed. The outcome of this goal is to understand better the various discursive knowledges of breast cancer, rather than to solve the 'problem' of it.

## **Knowledge**

Foucault demonstrated the changing nature of knowledge because knowledge is contextual. This is seen especially in the various disciplines of the social sciences.

## **The Disciplines**

Foucault characterised the disciplines as belief systems arising through specific sets of social, historical and political relations. He believed disciplinary knowledge resulted in practices that shaped the behaviour of others through their intimate knowledge of their subjects (Foucault, 1991). Application of Foucault's interpretation of the disciplines is particularly informative for my analyses of the constructions of breast cancer by the discourses deployed in such disciplines as medicine and sociology. Foucault (1977) states "Discipline 'makes' individuals" (p. 170). He saw discipline as a process of individualisation, not exercising power on an undifferentiated mass of the social body, but instead separating individuals as discrete entities and breaking the body up into many distinct parts. Foucault also saw discipline as individualising at the same time as it produces a normalising effect on the individuals it constructs (Foucault, 1977; Prado, 2000).

Foucault applied two different concepts or meanings of discipline - the first being the commonly-accepted professional discipline which is constrained and regulated by its

boundaries and codes of behaviour. But Foucault also developed a complex explanation of methods of practice which focussed on the function of disciplines as being rather more disciplinary than disciplining or punishing. While he did acknowledge the disciplines as fields of professional study in the more conventional sense, he posited them more as sophisticated systems of social control (Prado, 2000).

### **Normalising Judgements**

The goals of the discipline are often achieved by way of normalising judgements, which are integral to disciplinary practices in two ways. First, these judgements control the entry of members to the discipline and ensure their actions are congruent with the espoused values of that discipline. Breast surgeons, for example, are trained and socialised to think in terms of the altruism of breast cancer surgery, and to regulate their behaviour accordingly (Swick, 2000). Second, normalising judgements are the tools that disciplines use to measure and categorise the abilities or qualities of subjects. Foucault (1982b) identified this dual characteristic of discipline in the procedure of examinations. According to him, medical examinations for example, display the mechanics of power through technologies of visibility and documentation (Foucault, 1973). They measure the gaps and differences between subjects. Such judgements allow the discipline to assign a value to these abilities and qualities and establish what is normal for that category (Foucault, 1973; McCarthy, 2005). It is here that individuals are constituted as ‘cases’ or as subjected objects of power/knowledge relations. Foucault (1977) stated “The examination, surrounded by all its documentary techniques, makes each individual a ‘case’: a case which at one and the same time constitutes an object for a branch of knowledge and a hold for a branch of power” (p. 170).

In the hospital or breast care clinic, the normalising judgement of diagnosis determines which woman is healthy and which woman is diseased, who has breast cancer and who does not. So, at the point that a woman is diagnosed with breast cancer, she is constructed by medical discourse as a medical patient, and expected to conform thereon in to the behaviours expected of a cancer patient. A normalising judgement is not a negative criticism (Prado, 2000), but rather an assessment by disciplines of individuals and groups by way of comparison with a dominant belief system – a belief system that is considered by the disciplinary body of the time to be its objective, albeit bordered, quantitative truth. This is achieved through the focussed ‘gaze’ of the discipline.



## **The Disciplinary or Clinical Gaze**

Foucault contended that the disciplines have several perceptual fields or examination techniques that enable and sustain disciplinary discourses. The two techniques that are most apparent in the medical archive are what Foucault called the gaze and the confession (Osborne, 1994). Clinical medicine at the end of the 18<sup>th</sup> century set much store on visibility – on looking and seeing, and on visible symptoms – such as abnormal breast tissue. In *The Birth of the Clinic: An Archaeology of Medical Perception* (1973), Foucault charted how in less than half a century, the medical understanding of disease was transformed from the classical notion that sickness existed separately from the body, to the modern idea that disease arose from within and could be mapped directly by its course through the human body (McNay, 1994). This discursive shift was what Foucault called the medical gaze, (*le regard medical*). It changed modern medical practice because it gave greater importance to the clinical gaze which could now read the course of disease simply by an authoritative look at the visible body of the patient, following the “routes ... laid down in accordance with a now familiar geometry ... the anatomical atlas” (Foucault, 1973, pp. 3-4). This greater knowledge increased the medical physician’s power over the patient. The breast is a part of the female body upon which the discipline of medicine most definitely gazes by means of its many surveillance specialisms, and writes, by surgery, scarring, radiotherapy tattooing and other physical, emotional and social traces.

The normalising gaze of the examination classifies and judges human beings (Smart, 1995). It makes an individual an object, highly visible and therefore under the influence of the exercise of power. The gaze is constant, and the ongoing visibility maintains the treatment and subjecting of the individual as an object (Fairclough 1992). Being visible is how discipline affects women with breast cancer in hospitals, surgeries and clinics. The examination enables information about individuals to be kept in medical registries and files, allowing for commonly occurring features in a population to be documented. Through this process of the collection and manipulation of records, generalisations about the population can be made, leading to the calculation of averages, norms and percentages. Consequently, the individual becomes an object, a ‘case’. The examination is very much part of the experience of women with breast cancer, and the normalising gaze positions them as either ‘curable’ or ‘incurable’. Disciplines then, shape human beings, with or without their consent, and disciplinary power achieves its hold on individuals and collectives by observing, judging and examining (Smart, 1995).

A perceptual field that is conditioned by the dominant discourse of the time also gives the breast surgeon, for example, a specific frame of reference, circumscribing and directing what is actually seen when dealing with a breast tumour. The perceptual field guides the way the eye and other senses settle upon a tumour. It ensures that the gaze of the surgeon does not observe an isolated object called a breast tumour but is focused upon certain aspects of that structure according to the disciplinary norms that prevail at the time. The medical conditioning of the gaze ensures that the breast surgeon is trained to notice some things and not others (McCarthy, 2005). The gaze has thus been identified by a number of different writers as representing the process through which specific social objects, such as disease categories, come into existence and how more recent shifts to psychology, sociology and psycho-oncology, for example, can be seen as shifts in the disciplinary and clinical gaze (Armstrong, 1983, 1997). Foucault used the word gaze in an abstract way to refer to the fact that the body is not just the object of knowledge which is constructed, but also the object of the one who has the knowledge – the knower (Driver, 1994). The example in my study is the knower as professional doctor who engages in certain technologies of power and forms of discursive practices which allow certain statements about breast cancer to be made.

### **Power/Knowledge**

Another key concept which I apply in my study is Foucault's model of power relations - what he termed, as I have described earlier, 'power/knowledge' (Foucault, 1980; Gordon, 1980; Rouse, 1994). He joined the two words as one concept because he argued that there cannot be one without the other. Although Foucault refuted that he actually made the claim that 'knowledge is power' (O'Farrell, 2005), he was interested in studying the complex relations between power and knowledge without saying that they are the same thing. One of the most important features of Foucault's view was that mechanisms of power produce different types of knowledge which collate information on people's activities and existence. The knowledge gathered in this way further reinforces exercises of power. He developed the concept of the 'discursive field' as part of his attempt to understand the relationship between language, social institutions, subjectivity and power. Discursive fields contain a number of competing and contradictory discourses with varying degrees of power to give meaning to and organise social institutions and processes. Foucault's position on power relations contained four novel propositions, which are important concepts when applied to my study. These are

that power cannot be possessed, that power is productive, that power engenders resistance, and that power disciplines the body.

### **Power Relations**

Foucault's first position on power relations was that power cannot be possessed, but is executed in the ways people carry out certain activities and by the effect that that activity has on oneself and on others. The traditional thinking of power is that it comes from only one direction. 'From the top down' is a common idiom which reflects the thinking that power comes from a specific higher source – the sovereign, the state, the government, the manager, the doctor and so on. For Foucault, however, power is never monopolised by one centre, but is deployed and exercised through a net-like organisation (Foucault, 1980). An individual cannot hold power and therefore it cannot be handed from one person to another. Power cannot then, be possessed; it is only visible in its operations. Because disciplinary power is so dependent on alignments to the same practice, knowledge or outcome, it is not possible to simply remove the power from a given discipline and hand it over to the subjects (Little et al., 1999). For example, it is not possible for the doctor to hand over power to the patient or vice versa, as power is a network running through society and occurs in all social interactions. As just one example from the field of oncology, it is not feasible to take the control of breast cancer away from specialists and hand it over to the patients. In Foucauldian terms, such power is not in fact possessed by the doctors – it is relational, invested and transmitted through all the social groups associated with breast cancer care. All involved – patient, general practitioner, surgeon, oncologist, breast care nurse, pharmaceutical companies and carers – are all conduits of disciplinary power and all of them are subjects of that power (McCarthy, 2005).

Foucault's second position on power relations was that power is productive, and is exerted whenever a decision is made or an action is taken. Relations of power are intimately linked with social relations – within families and groups, and between doctor and patient. Foucault contended that power is exerted implicitly by the way in which our discursive interchanges and practices are formed. He argued that power is not a thing but a social relation, and is not always repressive, but often liberating. "... It needs to be thought of as a productive network which runs through the whole social body, much more than as a negative instance whose function is repression" (Foucault 1980, p. 119). Power is productive, especially with regard knowledge of oneself, and can be stimulating and reassuring. On the discovery of breast symptoms for example, most

women quickly become aware that they will, at some point, have to engage with others less familiar to them – a diagnostician, a surgeon, an oncologist. The relational self comes within the sphere of the power of these others. Whether the effects of power are beneficial or damaging is an empirical question which has to be addressed in relation to each particular case or situation. But in seeking a diagnosis, a woman is a subject who is seeking productive knowledge of herself, and this knowledge gives her power. We are all subjects, whether patient with breast cancer, partner or child, friend, general practitioner, diagnostician, surgeon, or breast care nurse, seeking a ‘truth’ which gives our knowledge its power and status. Within the power and knowledge relationship then, knowledge is a form of satisfying power and control (McNay, 1992), and this form of power is liberating, not repressive or constraining.

Foucault’s (1980) third position on power relations was that power engenders resistance and can be contested. It follows that productive power creates points of resistance to power which are repressive or constraining. Power is itself vulnerable by its drawing attention and exposing itself. Foucault (1978) says that “where there is power, there is resistance” (p. 95). In fact he went so far as to say that resistance is never absent from power. Where power is exercised, the potential for resistance is always formed because power is fuelled by resistance, and without resistance it is weakened and diminished. Resistance to disciplinary norms makes disciplinary power obvious because it sheds light on the very power structure that the individual is trying to resist. Rouse (1994), in analysing Foucauldian power/knowledge, describes how dominant ‘agents’ are constrained to sustain a certain alignment of power and the subordinates are therefore always in a position to challenge the aligned agent’s complicity in their disempowerment. Furthermore, the resistance of subjects enables actions and alignments with other power structures, and forces reflection on what is taken for granted (Grosz, 2005). There are many studies (mostly feminist) which have been sharply critical of what is seen as the medical establishment’s monopolising and appropriation of women’s bodies (Birke, 2000; Reed & Saukko, 2010; Ussher, 2007).

The concept of resistance has important implications for women with breast cancer, and for the health professionals who care for them. While neither party is powerless, there are occasions when their actions may be constrained by the actions of those around them. The setting for my study is the medical encounter, the place where patient and the medical system meet, and within which, I argue, there are opportunities for resistance or for the “intransigence of freedom” (Foucault, 1982a, p. 221). Foucault recognised that it

is possible, and sometimes desirable to resist disciplinary technologies. Resistances are formed at the point where relations of power are practised, and thus new opportunities emerge for the resistance of power within the lives of all individuals (Foucault, 1978). An individual can refuse, avoid, abstain from being part of the power play, or try to disrupt it. This is what Foucault termed the “strategic reversibility” of power relations (cited in Gordon, 1991, p. 5), and is seen in women who resist or who do not undergo regular breast examinations or mammography, or who conceal breast symptoms (Bloor & McIntosh, 1990; Vangelisti, 1994) and delay seeking a diagnosis (Andersen et al., 2009; Bish et al., 2005; de Nooijer et al., 2003; Macleod et al., 2009; Meechan et al., 2003; Morgan, 2003; Smith et al., 2005), or who seek alternative treatments and advice. Resistance by some breast cancer patients, in the form of their choice to reject chemotherapy treatment for example, illuminates some of the norms and less attractive aspects of power and oncology practice.

The fourth position that Foucault took on power relations was that power disciplines the body (Foucault, 1980). From the orientation to power relations presented above, power is seen to be a strategy that is exercised both on and through the body and through certain disciplinary institutions, such as the public health strategies of national breast health monitoring and disease surveillance through screening (Armstrong, 1983, 1994). Having power is having knowledge of how people’s behaviour can be affected. Because power is omnipresent and exercised throughout the social body, it operates at the most micro levels of social interactions, as in the medical encounter between doctor and patient. Relationships of power/knowledge permeate all levels of social existence, and therefore operate at every site of private and public social life. They are seen especially in some current techniques of social engineering, education, medicine and public health (Petersen & Lupton, 2000; Schneider & Lilienfeld, 2008; Turnock, 2009).

### **Technologies of Power**

For Foucault, the term ‘technologies’ referred to the practices, techniques or strategies of enacting or employing the power and knowledge gained from the human sciences. This notion of the technologies of power was primarily applied in Foucault’s model of the social body (Armstrong, 1994). He placed the body at the centre of the struggles between different formations of power/knowledge. Viewing disciplinary power historically, disciplines arose out of a need to manage increasingly large numbers of people during the 18<sup>th</sup> century. As a collective, people are unpredictable and hence dangerous, and against whom ‘society must be protected’ (Foucault, 1976). Foucault

explored how some disciplines accomplished the aim of making a population less dangerous by organising and training it in order to increase its productivity, whilst at the same time making it politically docile – the docile body (Foucault, 1977; Ransom, 1997).

Through a clinical or medical/public health gaze, the docile body is one that is “subjected, used, transformed and improved” (Foucault, 1977a, p. 136), or in the case of the specific population of women who require breast surgery, “laid bare, inspected, tested, penetrated, cut and reviewed in the process of surgery, reconstruction and improvement” (Twigg, 2002, p. 426). Such medical technologies and practices which allow the body to become known to others by being presented and viewed in new ways have been termed ‘objectifying practices’ (Finlay & Langdrige, 2007). It can be seen that disciplines such as medicine generate discursive practices of description and explanation whereby individuals are viewed and classified by experts and by themselves as normal or abnormal, healthy or unhealthy, diseased or disease-free and so on. As de Swaan (1990) puts it, “Sociologically speaking, everyone lives under the medical regime, a light regime for those who are not yet patients, stricter according to how dependent on doctors one becomes” (p. 57). Foucault developed particular notions of technologies of power by which populations and individuals are positioned under surveillance and thus policed and controlled. Two technologies of power through surveillance are especially pertinent to my study – panopticism, and confession (Foucault, 1977, 1978).

### **Surveillance**

It is not only disciplinary technologies which police both the mind and body of the modern individual (Dreyfus & Rabinow, 1989). Foucault (1977) also noted the application within institutionalised settings (especially the prison and the hospital) of an architectural design which reflected the developments in science of techniques of control and surveillance of whole populations (such as census data, epidemiology, and registers of demographic data) and surveillance of bodies (with developments in clinical medicine and anatomy). Jeremy Bentham’s concept design of the Panopticon penitentiary in 1785, which allowed all prisoners to be observed without being able to tell whether they were being observed or not, involved the notion adopted by Foucault of maximum supervision of self with minimum effort (Foucault, 1980; Armstrong, 1997; Eckermann, 1997). Foucault believed that the manner in which the Panopticon prison made the prisoners themselves the bearers of their own subjection could be

generalised to society as a whole. In other words, he used the term panopticism as a metaphor for the operation of disciplinary power in modern societies, not only in penal systems, but also in educational, military, medical, psychiatric, and psychological institutions. Each of these, Foucault (1977a) considered would play their part in “the formation of a disciplinary society” (p. 216). In Foucault’s analysis, disciplinary procedures such as medical examinations, breast examinations and scans, which simultaneously individualise and normalise the female social body, expand to become the techniques of surveillance characteristic of the panoptic nature of society – power embodied in the day-to-day practices of the medical professions within the clinic.

The second key Foucauldian concept of techniques of power, which I have applied in my study, is the notion of confession. If the Panopticon prison is the architectural metaphor for disciplinary power, then the confession is its ritual. The religious practice of confession provided information for the development of social sciences in the 18<sup>th</sup> and 19<sup>th</sup> centuries and used the knowledge to construct mechanisms of social control. Foucault argues that modern confession acts as a significant form of power and knowledge (Armstrong, 1995; O’Farrell, 2005; Spitzack, 1987), and in *The History of Sexuality, Vol. 1* Foucault (1978) makes clear the pervasiveness of confession in our society. We have

... become a singularly confessing society. The confession has spread its effects far and wide. ... one confesses one’s crimes, one’s sins, one’s thoughts and desires, one’s sillinesses and troubles ... to one’s parents, one’s educators, one’s doctor, to those one loves ... .Western man has become a confessing animal (p. 59).

That confession has become so pervasive in Western society has not been without consequence. These consequences are related to the productive nature of confession as a technology of disciplinary power. In other words, as mechanism of disciplinary power, “the confession became one of the West’s most highly valued techniques for producing truth” (Foucault, 1977, p. 59). Here, Foucault was not alluding to any real, objective truth, but rather to what is considered true. Confession, a technology of disciplinary power, can thus produce this ‘truth’. This is because the collected contents of confession - what the confessors say - are in turn used to classify the confessing subjects and produce truths about them.

The technology of power in confession also reflects Foucault's idea of pastoral power being the proper knowing of each member of the 'flock', both in terms of their history, and in view of their actual and prospective actions (Hook, 2003; Nettleton, 1997; Petersen, 1997). As Foucault (1982) explains, "this form of power cannot be exercised without knowing the inside of people's minds ... It implies a knowledge of the conscience and the ability to direct it" (p. 214). This is seen in the notion of 'caring' (Dean, 1999) and in the 'caring professions' such as medicine, which nonetheless serve State power interests while at the same time facilitating greater well-being. Medical consultations elicit the disclosures of individuals, but also encourage them to institute mechanisms of self-examination and conscience. There is an implied link between a thorough knowledge of oneself and an honest confession made to someone else, such as one's doctor.

A medical consultation and examination are together an example of a Foucauldian clinical gaze, juxtaposed to the woman who submits to a medical consultation in order to find the meaning of the lump in her breast as a type of confession. The confession is initiated by the patient in the form of supplying a health history and submitting to professional examination and care. In the Foucauldian sense, the confession makes individuals participants in their own control. In the medical encounter, patients contribute to the knowledge that the health profession has amassed by making themselves amenable to interview and examination. In doing so, they are more thoroughly able to be known and therefore, according to Foucault, more able to be controlled. Twigg (2002), observed how disciplinary technologies and practices can result in destabilising experiences for patients in health-care systems.

Hospital is an alienating experience in which the loss of sense of self that comes with the weakness of the body in illness is compounded by hospital practices that render their bodies subject to discipline and control, confined to certain areas, subject to regulations concerning eating and excreting, attached to machinery, exposed to view (p. 426).

Disciplinary technologies are powerful, at least in part, because of the way in which they involve people's bodies and habits such that people are themselves sometimes agents of control over themselves and over others.

Application of the Foucauldian principles of the technologies of power can be very clearly seen in examples from the breast cancer story. Through the hierarchical



observation techniques of panoptic-type medical and public health structures, individual women are set the self-surveillance task of monitoring themselves according to the values of others. How a woman responds when a breast symptom is first discovered is affected by the power of society's normalising judgements. She could be punished for non-conformity and irresponsible behaviour in taking no action, or rewarded for the expected, correct and responsible behaviour in seeking a medical consultation. The same could be said for her reactions to treatment decisions and adherence to treatment regimes. Health care is then, an area in which the panoptic gaze is greatly exercised. Its practice extends from the examination of a person by a health professional, to people regulating their own health, and to "...the control of whole populations in the name of public health, in the quest to normalise such populations" (Cheek, 2000, p. 30). Foucault (1978) called this form of power 'bio-power' or 'governmentality'.

### **Bio-power – Governmentality**

The concepts of bio-power (power over life) and governmentality were the result of Foucault's later work, and are thought by some to be his most considered approach to the concept of power (Moss, 1998). Bio-power and governmentality were the names given by him to the forms of power concerned with the management of life at both an anatomical and a societal level in order to fit people into institutional structures (Foucault, 1991; Bunton & Petersen, 1997). Bio-power emerged in the late 18<sup>th</sup> century alongside the development of capitalism (Lemke, 2001). It marked a break with sovereign power by virtue of the fact that it was interested in investing in and enhancing life, rather than deciding death as in sovereign power. Life became an object that power/knowledge acted upon. Foucault writes of the two poles of bio-power, the regulatory controls or 'bio-politics' of population, and 'disciplinary power' which focusses on the individual body (Foucault, 1978; Gastaldo, 1997; Rose, 2006). Disciplinary power is the disciplinary practices that construct the individual body as a machine, and the interventions that can occur with it (Hakosalo, 1991). It functions at the micro-level of the individuals, optimising their capabilities, and integrating them, through the route of a self-regulating subject. Bio-politics by contrast functions by gathering a massive body of information on the resources, capacities and problems of the population (Hook, 2003; Dreyfus & Rabinow, 1982).

Governmentality forms structures of power that manage people in order to produce a stable or docile social body. It views disease as central to economic processes and therefore legitimately subject to State and disciplinary control. The ends of government

rest in managing and developing the welfare of a population through the use of broader, more anonymous mechanisms of power, and the assumed responsibility of advancing and improving the standard, quality and longevity of subjects' lives (McNay, 1994). Areas of concern include: birth and death rates, reproduction, disease control and prevention rates, life expectancy, and what would cause these aggregate measures to vary. With particular reference to my study, this is especially relevant to public health campaigns directed at breast cancer prevention, through the collection of statistics and demographic characteristics (Petersen & Lupton, 1996; Simons, 1995). More directly related to breast cancer, bio-politics has two main techniques: mass cancer screening campaigns, which are used to manage large population groups, and techniques of disciplinary power which focus on the management of the individual body, such as mammography, biopsy, surgery, radiotherapy and chemotherapy. Bio-politics forge a docile body that can be used, transformed and improved for the benefit of society. The practice of breast self-examination is such an example, reflected in language for example, like 'examine yourself', with reference to public health campaigns urging women to routinely self-examine their breasts (New Zealand Ministry of Health, 2013). The urging of such campaigns is a promotion of the norms of healthy behaviour and self-discipline (Gastaldo, 1997; McCarthy, 2005), but which in their pervasive messages to conform also interfere with women's individual choice, thereby opening up conditions for the possibility of resistance.

Foucault has been important in locating the historical functions of the clinic as a site of bio-power (Foucault, 1973; Rose, 1993). This concept can be applied to the evolution of the modern-day breast care clinic, which is a prime example of a setting for the exercising of bio-power – the female breast as a focus for disciplinary bio-power of an individual woman, and for its governmentality through its knowledge and surveillance of an enormous population of women.

### **Technologies of the Self**

Foucault (1982b) developed the notion of technologies of the self as the practices or strategies of power one employs on oneself. In doing so, one 'subjectivises' oneself, becoming both the object and the subject of knowledge (Martin et al., 1988). Foucault described technologies of the self as the techniques that allow individuals to bring about changes by their own means or with assistance from others to their own bodies, minds, souls, and lifestyle, so as to transform themselves in order to attain a certain state of

happiness and quality of life - to make oneself better or to improve how one currently is, or perceives oneself to be.

Technologies of the self are a further component of governmentality – the micro-functioning within the field of power that subjects constitute over themselves (Martin et al., 1988; Rose, 1990, 1996a). There is a difference between technologies of self and disciplinary/panopticism, in that technologies of self are completely self-initiated and there is no hierarchical panoptic. As such, they are quite different in terms of the agency or capacity of individuals to act independently and to make their own free choices. The conceptual potential for self-surveillance nurtures self-discipline (causing an individual to gaze upon himself or herself ) which in turn can lead to the implementation of self-control – the calculating self (Miller, 2011). Self-surveillance thus emerges as a practice of control.

The increasing number of women with breast cancer who seek medical knowledge about the disease and treatment from the Internet are also resisting the face-to-face medical encounter. While subject to the disciplinary power of computer net-working they can be empowered by the knowledge they gain (Foucault's knowledge/power). By consulting medical websites they can gain information which sometimes makes them better informed than their GPs or nurses. Through modern IT such women become more educated in the norms of the dominant disciplinary alignment, and often, using such education, challenge them (Jordan-Marsh, 2011).

A breast cancer patient with an understanding of scientific principles can counter the scientific 'evidence' of the pharmaceutical companies underwriting chemotherapy clinical trials. If a manufacturer, for example, states that a certain cytotoxic agent confers a measurable improvement in the life span, an informed and thus empowered cancer patient can refuse such a trial on the grounds that a six week increase in life-span with a concomitant chemotherapy-related decrease in their quality of life is not an acceptable option (McCarthy, 2005). As this example demonstrates, the presence of resistance in power relations between the discipline of oncology and the woman experiencing breast cancer ensures that commonly-constructed subordinates such as breast cancer patients are never totally disempowered. Resistance emanates from within, and is based on and triggered by experience and prior knowledge (Good, 1994; Tritter & Calnan, 2002; Rosenbaum & Roos, 2000). As such, knowledge/power opened

possibilities for power to be challenged and disrupted by the women and health professionals in the medical setting of this study.

Self-governance then, is an imperative theme of governmentality which has an ethical component as well as a normative morality (Rose, 1996a). The ethical practices of technologies of the self stem from the self-choosing, self-activating subject's selection of values which, on the one hand are free from the moral assessments of recognised social authorities (Hook, 2003), but on the other hand are governmentally normalised forms of self-regulation. Normalisation is the ultimate goal and effect of disciplinary technologies – “the elimination of all social and psychological irregularities and the production of useful and docile subjects through the refashioning of minds and bodies” (Best & Kellner, 1991, p. 47). This entails subjects becoming ‘responsibilised’ by making them see social risks such as illness not as the responsibility of the State, but actually lying in the domain for which the individual is responsible, and transforming it into a problem of ‘self-care’ (Lemke, 2001). The practice of going for regular mammography, for example, can be seen as a result of responsibilisation - that it is women's responsibility to remain free of illness so as to be able to care for their families (Foucault, 1991; Roy, 2008; Shaver & Drown, 1986).

Such instruments of normalisation continually attempt to manoeuvre individuals and populations into “ ‘correct’ and ‘functional’ forms of thinking and acting” (McHoul & Grace, 1995, p. 170) in setting normative standards by which individuals monitor their own ethics and behaviour and think about themselves according to the norms produced from them. However, far from this normalisation making everyone the same, it magnifies individual differences, making them more visible. In this way, the liberating effect of technologies of the self allows the emergence of the non-conformist, but the non-conformist quickly becomes the object of disciplinary attention. Thus technology of power of the techniques and ethics of the self is profoundly ambiguous because it paradoxically enables while it simultaneously subjugates individuals.

### **Subjectivity/Identity**

As his work developed, Foucault (2001b) became much more concerned with questions about ‘the subject’, and as described in the preceding section of this chapter, his late and unfinished work gave the subject a certain reflexive or self-analytical awareness of his or her own conduct. He explored how people make themselves subjects, and how they transcend these subjectivities by becoming more aware and active participants in their

own control and in their acquiescence to the manipulation of their bodies, minds and behaviour in order to improve themselves.

Subjectivity is produced through discourses that are multiple, possibly contradictory and unstable – described as “discursive battle(s)” (Gavey, 1989, p. 471) between a subject positioning in one discourse and another position within this or some other discourse, at this time and not at some other time. Through more self-awareness, the assuming of a particular subjectivity gives one ‘allegiance’ to a particular discourse, and this can be either be motivating or discouraging for the individual. The deployment of a particular discourse is not accomplished by a new discourse replacing old ones. It is a result of contradictions in subject positionings which result from the coexistence of the old and the new. Post-structuralists suggest that some conflict like this is inevitable and is the source of the changeable and contradictory nature of subjectivities or identities (Crossley, 1994; Hollway, 1989; Ransom, 1997).

Because the availability of subjectivities is limited by social context and power relations, and compete with one another at the level of the individual, they vary in terms of the power they offer (Woodward, 1997). Individuals gain knowledge and assume subjectivities through having direct and personal experiences, through the experiences of people with whom they interact, as well as those depicted in all other forms of communication. Post-structuralists argue that in order to understand how a person’s sense of self is constructed, not only the biological but also the social and psychological factors which contribute towards its construction should be considered (Rose, 1985).

This critical change of focus is illustrative of Nikolas Rose’s (1985) concept of the ‘psy-complex’. This refers to all the ways that the discipline of psychology (and related areas like psychoanalysis, psychotherapy, psycho-oncology) has been involved in shaping people’s practices and understandings of their emotional selves, and in the regulation of these subjectivities (Lazarus, 2006; Lupton, 1998; Tamboukou, 2003). The study of the emotional and psychological aspects of life has become so pervasive Rose (1996a) says, that “it has become impossible to conceive of personhood, to experience one’s own or another’s personhood or to govern oneself or others without ‘psy’ ” (p. 139). He argues (1990) that the proliferation of the ‘psy’ disciplines has been intrinsically linked with transformations in governmentality or the rationalities and technologies of political power. So, in order to conduct a discursive analysis of the processes by which the participants in this study were made subjects, based on Foucault’s theories and

concepts, I had to also consider the impact of the psy-complex in determining how they constructed themselves emotionally, how they constructed others and in turn how they were constructed by others.

## **Summary**

In this chapter I have described the epistemology of post-structuralism in which this thesis is located, and have broadly identified the main ideas from Foucault's work that are pertinent to my study. I have emphasised the importance of his concept of discourse, and his notions of archaeology, genealogy and history of the present as the tools by which he analysed discourse. Foucault's approaches are not easy to summarise, but the main objective of this chapter has been to describe his concern with discourse's interconnectedness to power, knowledge and truth. In this chapter I have focussed on how his notions of identity, subjectivity and self are the primary vehicles of power's implementation. Each interconnection has relevance for this study and offers insights into the constructions of the experience of breast cancer by the women participants, and by the health professionals who care for such women.

In the following chapter I describe the methodological approach I applied to my study, and the steps involved in my research method.

## **CHAPTER THREE: METHODOLOGY AND METHODS**

### **Introduction**

The methodology used for this study is most appropriately described as a post-structural discourse analysis, drawing on the work of Foucault. In this chapter I describe my application of post-structural discourse analysis, and the key Foucauldian ideas most applicable to my research upon which I drew to construct the methodology for this study. I also describe the research methods and steps I took to conduct the study. These include my research design, the criteria and process used to select the participants and the sites of recruitment. I describe the form of the interviews and the processes of interviewing, recording, transcription of interview content and data analysis. I explain my attempts at ensuring rigour or the validation of my research approach, and how I addressed the ethical issues related to my study.

### **Post-structural Discourse Analysis**

Broadly, discourse analysis refers to a set of methods that have been used by researchers with different theories of language in a variety of ways (Allen & Hardin, 2001; Arribas-Allyon & Walkerdine, 2010; Gill, 2000; Tonkiss, 2004; van Dijk, 1996; Willig, 1999). As described in Chapter Two, the key notions of post-structuralism are truth, subjectivity, and the historical and social nature of knowledge (Besley, 2002; Foucault, 2003; Harrison, 2006), and post-structuralist thinkers conceive of social spaces (organisations, institutions, social categories, concepts, identities and relationships), and the world of material objects as discursive in nature. The power of the word, in both its written and spoken form, is a primary determinant in how we experience ourselves and others within the world, and how we interpret those experiences (Crowe, 1998). The main focus of post-structural analysis is on the content of the texts – that is, what is actually said, done and written (Tonkiss, 2004), as everything is text. This claim is commonly known as ‘there is nothing outside the text’ (Derrida, in Naas, 2003, 2008). A second basic tenet of post-structuralist theory of discourse is that the process of meaning making in relation to people and objects is caught up in an infinite play of difference and equivalence. Meaning is never finally fixed; it is always in an unstable flux (Wetherell, 1998).

Post-structural discourse analysis tends to divide texts (anything spoken, written or acted that can be read for symbolic meaning) into specific discourses (Fairclough, 2003;

Stevenson, 2004). Research such as this is able to ask questions about social interactions which can be addressed systematically through a qualitative approach (Given, 2008). One of the achievements of post-structuralism is the radical way in which it has placed discourse analysis at the heart of the social-scientific endeavour (Alvesson & Kärreman, 2000), and is a method which has been shown to offer particularly valuable insights into social, emotional and experiential phenomena in health care (Candlin & Candlin, 2002; Cheek, 2004; Cheek & Porter, 1997). In the early 1990s, Lupton (1992) advocated the employment of post-structural discourse analysis to address what she saw as the inadequacies of traditional research into attitudes and behaviour in relation to health. She suggested that the methodology was “a valuable way of understanding the underlying assumptions inherent in health professionals’ communication with their clients, lay health beliefs and the messages and meanings about health issues disseminated in the popular media” (p. 149). Post-structural discourse analysis has since gained steady momentum as both a research methodology and a research method over the past three decades, and it is now readily taken up by health researchers, particularly in relation to health policy and health education (Cheek, 2004; Cohen & Crabtree, 2008; Crowe, 2005).

Post-structural discourse analytic research tends to ask more deconstructive what, how and why-type questions, rather than whether or how much (Burman & Parker, 1992, 1993; Cheek, 2004; Cohen & Crabtree, 2008). As such, its strengths are in its potential for multiplicity in accounts and its rejection of straightforward representations. When applied to the field of health care, post-structural discourse analysis has often included enquiry about the meaning of illness to individuals, and the attitudes and behaviour of patients and clinicians, subjects of interest directly pertinent to my own study. Because language is a material and social process, the social and historical contexts of speakers’ accounts are important considerations. In my study, the accounts of experiences of breast cancer were analysed as a process within their particular cultural and social contexts (Griffin & Bengry-Howell, 2007; Malterud, 1993; Rustin, 2000; Wilkinson, 2000). This method of discourse analysis construed each of the study participants as embedded in his or her social context, making use of what Morgan (1999) called their ‘social resources’ to constitute their experiences, whether of health, illness or professional practice.

One of the difficulties of post-structuralist discourse theory is undeniably its failure to be explicit about how to engage with the analysis of actual instances of text or social



interaction-in-context (Harrison, 2006; Potter & Wetherell, 1994). The practice of post-structural discourse analysis is challenging for researchers because there are no recipes or formulae by which to conduct the analyses of both the language used and the wider social context in which the language is used (Jørgensen & Phillips, 2002). Post-structural discourse analysis is therefore, not a straightforward matter of complementing discourse theory with empirical analyses of text and talk. The main challenge for researchers of discourse has been how to reconcile the need to be explicit about methodology with a non-essentialist and non-positivist view on the production of knowledge and power (Jørgensen & Phillips, 2002). Methods of post-structural discourse analysis have particularly brought to the fore the crucial role of discourse in its capacity to identify sites of hegemonic power. Language is one of the ways that hegemony is established culturally and socially, and these kinds of analyses are particularly helpful in the investigation of women's power over their bodies and their health, and illnesses such as breast cancer (Malterud, 1993; Schulzke, 2011; Ussher, 2007). They are also useful in examining health professionals' constructions of these illnesses, and the medical conditions in which they specialise. The philosophy of post-structuralism, the methodology of post-structural discourse analysis, and Foucault's concepts of discourse, truth and subjectivity and techniques of power offered me a way of deconstructing the conditions of possibility of the dominant power/knowledge complexes in the specific context of the medical encounter (Howarth, 2000; Powers, 2001; Ransom, 1997).

### **Applying Foucauldian Methods to My Study – How Foucault Fits**

As I outlined in Chapter Two, Foucault's particular interest was in the ways that language as a social process constructs objects, subjects and experiences within structures and techniques of power. His concern was not only with ideas and their development, but with the social relationships and political changes which make certain ideas more possible at particular historical moments. For Foucault, the humanist discourses of modernity were knowledge systems which informed institutionalised technologies of power. His main interest was therefore, in the origins of the modern human sciences (such as, psychiatry, medicine, sexology), the rise of their affiliated institutions (the clinic, the prison, the asylum, etc.), and how the production of 'truth' is governed by discursive power regimes. To reiterate, according to Foucault (1972), everything that we are familiar with in our world is formed and reformed through discourses, and beyond this we are not completely in control of meaning. We not only

use, but are also used by discourses (Parker, 1998; Stevenson, 2004) in their various sources of power, and in turn power relationships.

Post-structural discourse analysis in itself is not a homogeneous research approach by which to deconstruct these meanings, and Foucault in particular, did not provide a clear framework by which to undertake it (Kendall & Wickham, 1999; Willig, 1999; Willig & Stainton-Rogers 2008). Rather, using Foucault's concepts of discursive practices and power relations as the framework for reading text, it is in a sense one's own version. My discourse analysis involved the careful reading of literature and transcribed texts of interviews, with a view to discerning discursive patterns of meaning, contradictions and inconsistencies. This approach identified and named the discursive processes, for example, those processes my study participants employed to constitute their understanding of breast cancer and accounts of breast cancer treatment. These practices were related to the reproduction or distribution of power and knowledge within the institutions of medicine and public health, between the women patients and health professionals.

Post-structural discourse analysis researchers are interested in actions and interactions in context, from the point of view of the participants involved. They (the researchers) are required to enter the setting with open minds, prepared to interact with their participants and immerse themselves in the complexity of the situation. More specifically, this type of research is an approach to gaining knowledge based on the notion that beliefs, goals and activities are produced by discourses, and are not seen as essential drives or motivations (Arribas-Ayllon & Walkerdine, 2010). As such, post-structural research does not typically generate 'answers'. Decisions about data analysis are made in response to the nature of the phenomenon being investigated as its constitution is revealed, with interpretations developing and changing along the way (Arribas-Ayllon & Walkerdine, 2010; Fischer, 2006; Holliday, 2007; Parker, 1999; Phillips & Hardy, 2002). When I considered all of the above characteristics of post-structural methodology and research methods, I believed they were well suited to my research because of their ability to analyse first-hand accounts of women experiencing breast cancer, as well as of health professionals.

The first goal of my study was to identify and analyse the most dominant discourses by which the women and the health professionals constructed breast cancer. A dominant discourse in a post-structural sense is seen as the 'accepted' line and the 'normal' range

of talk about the subject (in this case, about breast cancer and its treatment) what is included and excluded, what was said and not said, by whom, and in which settings (Foucault, 1972). A discourse may be also dominant because it remains very stable over time, and the range of alternative representations generated by it is limited. Rules are formulated for the repeatability of statements or the conditions which allow certain statements to recur and to become dominant (Hall, 2001). These are, by way of illustration, the procedures used by government authorities and health practitioners to deploy certain statements about breast cancer (Foucault, 1991). An example is medicine's and public health's constructions of breast cancer as a significant 'killer disease' of women, and through those constructions, the urging of women to have regular breast examinations and mammography.

Discursive inclusions and exclusions depend on people's positions in the world, their social and personal identities, and the social relationships in which they stand with others (Davies & Harré, 1990; Hall, 2001; Foucault, 1972). The relationship between different discourses is one element of the relationship between people. One or some discourses can complement, supplement, compete against, or dominate other discourses resulting in strength or dominance of a discourse. Discourses thus constitute part of the resources which people deploy in relating to one another. A most telling setting for these social interactions is the medical encounter between patient and health professional (Foucault, 1973; Goodyear-Smith & Buetow, 2001; Leopold, 2000; Little et al., 1999). My analysis was conducted within the texts gained from semi-structured open-ended interviews. Such texts are very suitable material for a post-structural discourse analysis because of its facility as a research method and analytic tool to access what the participants did and what they experienced being done to them, and to analyse the continuity and discontinuity of these experiences over time (Foucault, 1989).

## **Methods**

In the following sections I describe the methods I used to obtain the texts for analysis and the ways in which the analysis was conducted.

### **Selection of Participants**

The selection of participants for qualitative research involves making decisions about which people, settings, events, behaviour and/or social processes are to be examined (Denzin & Lincoln, 2005). Samples for discourse analysis studies are generally small (Crouch & McKenzie, 2006; Mason, 2010; Ritchie et al., 2003). This is because the

research is concerned with meaning rather than providing information by which to make wide and generalised hypothesised statements (Crouch & McKenzie, 2006).

Discourse analysis research is very labour intensive, so analysing a large sample can be time-consuming and often impractical. Nevertheless, within any research area, different participants have diverse opinions. Samples must be large enough to assure that most or all of the perceptions that might be important are uncovered, but at the same time if the sample is too large, data becomes repetitive and, eventually, superfluous (Mason, 2010). There is a point of diminishing return to a qualitative sample - as the study goes on more data does not necessarily lead to more information (Denzin & Lincoln, 2005; Liamputtong & Ezzy, 2005; Mason, 2010). For Denzin and Lincoln (2005), selection meant that the researcher delineates the relevant unit(s) of analysis precisely, using criteria based on specific considerations, and then selects participants and/or phenomena for study that meet those criteria. Because this type of research is concerned with in-depth analysis and detail, researchers deliberately select small samples that fit the research questions and aims. This underpinned my decision to include as participants only women who had personally experienced breast cancer and its treatment, and health professionals who had engaged in the care of women with breast cancer.

### **Participant Groups**

I interviewed two main participant groups – women who had personally experienced breast cancer and its treatment, and health professionals who worked with women with breast cancer. I chose these two groups because I considered them to be closest to the discursive object under investigation, rather than others positioned more remotely (Coyne, 1997; Brink, 1991). These two groups would be having, or would have had, the experiences most directly relevant to my research questions. The women participants and the health professional participants were not known or identifiable to each other.

Following Mason's (2010) recommendation that fifteen is the smallest acceptable sample, and Green and Thorogood's (2004) finding that little comes out of transcripts after twenty or so people (in each participant group) have been interviewed, I recruited and interviewed a total of 37 voluntary participants - 20 women (aged between 34 and 77 years) and 17 health professionals. Women returning to a medical setting for a regular annual follow-up mammography, and who met the inclusion criteria were invited through word-of-mouth by a breast care nursing co-ordinator to take part in the study.

Twenty women were interviewed for the study. The women were not questioned directly about their ethnicity, marital status, sexuality, socio-economic and employment status, religious affiliation and so on. The majority of the women were aged between 40 and 50; most spoke of being married, mothers or grandmothers, and most were also in some sort of employment. Because of the site of recruitment of the participants, most of the women spoke about having private medical insurance, but not all.

Seventeen health professionals were interviewed. Their respective medical disciplines are listed in Table 1. One health professional identified herself as Maori.

**Table 1.** Participants Interviewed for the Study

<b>Type of Participant</b>	<b>Number</b>
Women	20
General Practitioners	4
Oncologists	3
Breast Surgeons	4
Psycho-oncologists	2
Breast Care Nurses	2
Practice Nurses	2
<b>Total</b>	<b>37</b>

In order to ensure that both the women's and the health professionals' voices were heard (Derrida, 1982) participants were selected on the basis of purposive sampling. That is, they were selected for the specific purpose of gaining a better understanding of the discourses deployed in relation to breast cancer through the descriptions of their experiences (Brink, 1991; Coyne, 1997). Interviewing both women and health professionals added breadth and complexity to my data by giving different, and possibly contradictory accounts, or accounts from different perspectives (Seidman, 2006). The purpose was to explore how they were positioned in relation to one another. This positioning was important because it showed what spaces or positions the discourses

offered or were taken up by the women and the professionals. The criteria that I used for the selection of participants are described below.

### **The Women**

The criteria for participation were that the women had to be over the age of twenty-five years, and had personally had a diagnosis, and had undergone medical treatment for breast cancer. Two time limits restricted the women participants to those who had completed their last direct medical intervention (except, for example, on-going regular consultations and/or anti-cancer medication) at least twelve months prior to the interview, and up to a maximum period of five years after their last treatment.

The first reason for interviewing only women who had already been through their own breast cancer experience, rather than women who were undergoing it at the time of the interview, was to get a synopsis of their experiences from the discovery of symptoms to recovery from their treatment/breast cancer.

The second rationale for not selecting women who were experiencing breast cancer at the time was that the process of being interviewed might have added to the anxieties and fears they were undoubtedly feeling about what they were going through. Undergoing treatment for breast cancer is a difficult, and often an emotional experience for most women (Galgut, 2010), and is therefore an emotionally-charged topic to study. As such, it meets the criteria of McCosker et al., (2001) and Renzetti and Lee's (1993) definition of a sensitive research topic - "one that potentially poses for those involved a substantial threat, the emergence of which renders problematic for the researcher and/or the researched, the holding, and/or dissemination of research data" (p.5). I believed that talking about one's experiences of breast cancer would be an extremely personal, sensitive and emotional issue for the women, so talking to them after the event decreased the possibility of stirring up emotions. I considered that it would have been unethical to aggravate any concerns that they might have and to expose them to any other possible unsettling scenarios (Morse, 2002; Reinharz & Chase, 2002; Renzetti & Lee, 1993; Oakley, 1981; Yardley, 1997).

The third reason for my stipulation of the time limit to a maximum of five years was that the authenticity of the women's recollections of any traumatic or stressful events could have been clouded by the passing of a longer period of time than this (van der Kolk & Fisler, 1995).

## **The Health Professionals**

The process of recruitment of the health professional participants was that I personally approached them and asked if they would be interested in taking part in the study. I was given the names of those who were working within the network of a city breast clinic by the nursing co-ordinator of that clinic. I contacted each person by phone or met with them face-to-face. The criterion for eligibility was that they were currently working in any of the fields of general practice, diagnosis, treatment or care of women with breast cancer. This group included GPs, breast surgeons, oncologists, breast care nurses, general or practice nurses, and psycho-oncologists.

Those individuals who initially expressed an interest and a willingness to take part were then given a *Participant Information Sheet* (Appendix C: *Information Sheet for Women* and Appendix D: *Information Sheet for Health Professionals*) which provided more information about the study.

All potential participants were given two weeks to consider their involvement, and then asked to contact me directly, at which time I set up an interview date and time at a venue of their choosing. If they did not contact me, no further approach was made. At the initial interview I reiterated what the study was about, answered any questions the recruits had, and explained the Informed Consent form (Appendix E: *AUT University Consent Form*), which they signed and provided a copy.

In accordance with the research methods of interviews (Guest et al., 2006; Mason, 2010) and discourse analysis, the final number of participants was determined when contradictions and multiplicities recurred in the content of the interviews (Mason, 2010).

## **The Interview**

### **Content and Process**

To obtain qualitative data within the health field, research questioning should allow the participants to identify for themselves the topics and issues of importance within the broader research questions (Atkinson & El Haj, 1996). Data are usually verbal and/or visual and can be collected using both interactive and non-interactive methods (Rubin & Rubin, 1995). I decided to collect my data by means of interviewing and using a digital voice recorder to record the content. One-on-one or face-to-face interviewing has become the most common type of qualitative research method used when investigating

people's experiences in context, and the meanings these experiences hold (Fontana, 2002; Fontana & Frey, 2000; Hutchinson & Wilson, 1994; Mishler, 1984; Perry, 2009; Rosenthal, 1993). I chose to use interviewing as my method of inquiry to gain an understanding of the participants' experiences as expressed in their own words. While the structured approaches of standardised questionnaires and surveys can be used effectively in post-positivist, interpretivist and critical research such as ethnographic and feminist studies (Westmarland, 2001), they were inappropriate for the type of post-structural and Foucauldian research I wanted to carry out. The questions in questionnaires and surveys can be slanted in ways which presuppose what respondents might say, rather than allowing respondents to express themselves in their own terms. What they say, and how they say it, is thus opened up and available for discursive analysis (Holstein & Gubrium, 1997; Seidman, 2006).

The appropriate interview method depends upon the topic (Mishler, 1996), and I elected to conduct individual interviews rather than group interviews, because individual interviews tend to be more useful in evoking candid disclosure of personal experiences and perspectives, particularly on sensitive topics (Giacomini & Cook, 2000; Morse, 2002). I used a semi-structured, open-ended interview technique because I wanted to capitalise on Potter and Wetherell's (1987) goal of having participants elaborate on their views in a relatively naturalistic conversational exchange. Mathieson (1999) recommended the semi-structured open interview format as especially suited to studies of the changes that characterise the transition from health to illness, especially with regard to "the initial impact of diagnosis, the stressors of treatment, changed relationships with family, friends and employers and new and old relationships with health-care providers" (Mathieson, 1999, p. 118); topics that were also of great pertinence to my study.

Because I needed the interviews to cover the same topics more or less systematically, I used interview guides (Giacomini & Cook, 2000), what Hollway and Jefferson, (2008) called "initial narrative questions" (p. 125), as prompt sheets for myself, and then simply asked the interviewees to talk about their experiences of breast cancer (whether as patient or health professional). My rationale for letting their associations take them to wherever they led within the interview was two-fold. Firstly, because my aim was to draw out the dominant discursive positions and practices, I believed that the insights gained would be more consciously revealing. Secondly, I wanted to minimise the risk that I would presume or introduce unintended meaning to what the participants were



saying (Hollway & Jefferson, 1997, 2008). For example, one might imagine when asking a woman to talk about her experience of breast cancer that she might start from the point of diagnosis. I found however, this was often not the case. Of the 20 women interviewed, seven began with their experiences of seeing another woman die of the disease.

### **The Interviews with the Women**

During the course of the one interview the women were encouraged to talk freely about their experiences of having breast cancer, the circumstances of the diagnosis, the health professionals with whom they engaged, the treatment regime they undertook, and about the period of their recovery. The interviews took place in a setting of the women's choice. All settings were private and quiet. Most of the interviews were conducted within their own homes, some in their work-place or mine. None of the women chose to have a support person present or close by, even though this was offered.

### **The Interviews with the Health Professionals**

The health professionals were asked to talk about their experiences of working in the field of breast cancer, their engagement with women with breast cancer, and of providing services and care to women throughout diagnosis, treatment and recovery. Most of the interviews took place in a quiet and private place within their work-places.

### **Interview Process**

The interviews were conducted in such a manner that they resembled a natural verbal exchange rather than a formal questioning session. Questions were open-ended and focused on what, how and why (Giacomini & Cook, 2000), thus eliciting personal information and enriched stories. These questions and I believe my honest interest, attentiveness and respect for what the participants were saying, encouraged them to share their narratives, which I recognised as valuable descriptions of their making sense of their experiences within their unique contexts. Open-ended questions were also used to avoid limiting their talk, and as an attempt to avoid my imposing any moral, ideological or theoretical frame of reference onto the participants' experiences which might have led to them describing their experiences in a particular way (Giorgi, 2005).

As an interview progressed, I reflected on what I was being told, and sought clarification if necessary, in order to verify my understanding of the narratives and to encourage the participants to elaborate further. The aim was to elicit as much detail as

possible. The face-to-face interviewing allowed me to remain alert to any recurring content and patterns which emerged during the interview, to which I could continue, or return to question further (Fontana, 2002). In addition, the interviews provided me with the opportunity to interact with the participants on a personal level. Priority was given to establishing good rapport with the participants and to creating a feeling of safety and comfort. Due to the sensitivity of the topic, particularly for the women participants, an unusual degree of rapport needed to occur, and some self-sharing eased the process (Jack, 2008). During each interview, I attempted to maintain a participant-centred style of interaction, by exhibiting warmth, empathy, humour and unconditional positive regard, in order to encourage the participant to speak freely and congruently about his or her experiences (Jack, 2008).

### **Recording of Interviews and Transcription**

The interviews were recorded on a digital voice recorder and downloaded onto a computer using an electronic DSS digital transcriber hardware programme. In order to meet the ethical requirements of safe-guarding the study participants' confidentiality, pseudonyms were used in place of their real names. This was the case for both the women and the health professionals. Transcribing appears to be a straightforward technical task, but in fact involves judgements about what level of detail to choose (Maclean et al., 2004). I was faced with the dilemma of which practice of transcription to use, and how verbatim the final transcript for discourse analysis would be. Silverman (2006) noted that post-structural and Foucauldian discourse analysis does not require the absolute precision in transcriptions that more pragmatic approaches to language, such as conversation analysis, do. For my purposes, accuracy in my transcriptions concerned the substance of the interview, the meanings and perceptions created and shared by the interviewees (Bailey, 2008; Jefferson, 1996).

### **Data Analysis**

Post-structural data can be analysed in various ways. In some cases elaborate coding systems are used, and categories and patterns emerge from, rather than being imposed on the data that has been obtained (Ritchie et al., 2003). Because the focus for my research was more on a continuous process of analysis than on a set of fixed procedures, the analysis of data was in a sense a personal process, but one which was guided for me by key post-structural and Foucauldian principles and concepts. I did not develop or use any orthographical or lexical system of data analysis because the aims of my

investigation were more content- or construction-orientated than language-orientated. That is, I was more interested in what the participants said and did not say, (because absences were also important) rather than how they actually spoke through the mechanisms of their speech delivery.

After the interviews, all of the recordings, in their entirety, were transcribed into hard copies by the transcriptionist, who had signed a *Confidentiality Agreement* (Appendix F). My first task was to check for transcription accuracy by simultaneously listening to the tapes and reading the transcripts. I then read and re-read every transcript in order to thoroughly familiarise myself with the data and to gain an overview of content. Parker (1992) said that because a discourse is interrelated to other discourses there are points where a discourse may intersect with, involve or infer another. The interview transcripts were analysed singly, that is, one by one. Each transcription was read and re-read in its entirety, and analysed as a whole piece of text separately from the others. This was an attempt to capture the whole essence of each participant's personal experiences or 'story', and to avoid contamination of research data from, or transference of, information from other transcripts. The dominant discourses and associated subject positions and subjectivities emerged and became identifiable as they were plotted on the interpretive grids rather than as the result of a 'layering' of themes by searching for them across all of the transcripts at the one time.

I worked from the printed hard copies and because of a lack of any formal structure of data analysis, I developed my own system for collating the information so that themes, patterns, layers and links could be identified across the whole corpus of the raw data. As I read the transcripts, I could see that the women and the health professionals seemed to spontaneously talk about four stages of the breast cancer experience - discovery, diagnosis, treatment and recovery – and that there seemed to be different subject positions moving in and out of the illness trajectory. By using these four terms created by medical discourse, I imposed a structure over the analysis by delineating the four stages of the breast cancer experience. This provided me with a sharpening of focus and helped me to manage the large amount of data obtained from the interviews. By locating the discourses in a time or place, I was able to trace their emergence in the chronology of the participants' accounts. This process was similar to that described by Grbich (2004) as being from "the outside looking in" (p. 42). By this she meant the identifying of thinking, statements, challenges and arguments which emerged as themes, and which could remain constant throughout an account or could change direction.

I used different coloured pens to highlight what I saw as discourses and Foucauldian aspects of discourse as they arose within the text. Parker (1992) wrote that “discourses embed, entail and presuppose other discourses to the extent that the contradictions *within* a discourse open up questions about what other discourses are at work” (Parker 1992, p.13) (emphasis in original). I then drew up grids (Smith et al., 1999) on large sheets of poster paper to provide me with a visual overview, and to enable me to plot content and visually trace relationships between the content (refer to Table 2). I was thus able to discern the dominance of a discourse by the degree of repetition with which it occurred, and to compare the strength in which it was shared or bounded by certain groups of people or excluded others (Foucault, 1972; Parker, 1992).

**Table 2.** An Example of an Interpretive Grid**Stage of Breast Cancer Experience: Treatment**

	<b>Discourse A</b>	<b>Discourse B</b>	<b>Discourse C</b>
<b>Discursive Object</b> What is being constructed			
<b>Subject Position</b> Role or name of speaker's position as related to discursive object			
<b>Subjectivity/Identity</b> Personality, persona, understandings of the world			
<b>Discursive Practices</b> Actions/behaviours related to subjectivities			
<b>Technologies of Power</b> Techniques and strategies of power relations			

In order to explore the discursive objects and subject positions being brought into play in the participants' accounts, I used four main Foucauldian discourse analysis guidelines suggested by Arribas-Ayllon and Walkerdine (2010) for conducting my analysis. My first step was to select a "corpus of statements" (p. 98) from the transcripts of each participant's account. A corpus of statements is the sample of text which I highlighted as expressing or constructing the discursive object of the relevant part of the findings e.g. the treatment stage of the breast cancer experience. Such a stage allowed for the discursive object to emerge, and for me to be able to identify and name it. The corpus of statements also allowed me to check if the breast cancer experience was talked about differently by the various speakers from their different positions, and if, how, and why

their perspectives changed over the stages of discovery, diagnosis, treatment and recovery.

The second step was for me to look for and identify examples of where the discursive object of breast cancer, now named, was constructed as problematic or vexed by the speakers. Foucault's (1998) concept of problematisation was a device of inquiry which offered me a potential view into the conditions of possibility of the emergence and submergence of certain discursive formations and practices around breast cancer (Deacon, 2000; Fosket, 2000). According to Foucault, problematisations are tensions between power and knowledge which often form at the intersection of different discourses, and expose those practices which are constructed as problematic. Problematisations also provide bases for the elaboration of new practices which can provoke solutions to those tensions.

I next identified and explored the technologies or the practical forms of power deployed by the participants for the management of themselves - Foucault's (1982b) technologies of the self, and the deployment by others for the governing of the participants from a distance - Foucault's (1991) concept of governmentality. As described in Chapter Two, these were the two kinds of technologies of power particularly pertinent to my study. This step in the analysis enabled me to explore the technologies of self by which the individual speaker sought to regulate and enhance his or her own conduct in local and specific social interactions. Both technologies of management of self and governmentality have political kinds of intent, as there is often an alignment of technologies of self with broader political and other interest groups (Rose, 2006).

Identifying the various subject positions offered or imposed by the discourses showed me where the women and the health professionals grounded their claims of truth and responsibility (Arribas-Ayllon & Walkerdine, 2008); Foucault, 1972; Parker, 1992). The process also gave me an insight into how they each, both as individuals, and in their identification with others in similar circumstances, managed their moral locations within their social interactions with each other. This gave me a good understanding of the subtle and complex subjectivities or identities which emerged. It was also informative about some of the ethics or morals, and moral agency of this self-formation, including through which practices and by what authorities the participants regulated their thoughts and behaviours (Foucault, 1988).

Having plotted examples from the texts of the characteristics of Foucauldian discourse on the grids, I again used highlighter pens to circle those that appeared most frequently. The grids thus allowed me to identify at each stage of the breast cancer experience the principal discursive object, and links between the subject positions, subjectivities and discursive practices deployed by the participants, and the any technologies of power at work. In this way I was able to not only understand the relationship of the women and the health professionals to the identified discursive objects, but also the networks of power relationships which positioned the women in relation to the health professionals and vice versa (Parker, 1992). This was a crucial part of my analysis in the defining of issues which were identified in the women's and health professionals' interactions with each other. The challenge was to ensure that the issues identified reflected the concerns of the interviewees as indicated in their narratives, rather than merely reflecting my own pre-defined set of categories. Overall the process facilitated an analysis of the interplay of the identified dominant discourses and the effects of this interplay on the speakers.

### **Rigour/Post-structuralist Validation Strategies**

#### **The Validation of Post-structural Research**

From the late 1980s, with the increasing influence of post-positivist values on scientific research, there was a more general acceptance of non-positivist values on qualitative research approaches (Tashakkori & Teddlie, 2003), and a widening of a variety of qualitative methodologies from different paradigmatic positions. Limitations in the scientific understanding of rigour and generalisability of research findings became apparent in this shift and the concept of rigour also expanded. Over time qualitative researchers have moved away from the traditional concepts of empirical rigour of reliability, validity and generalisability (Hall, 1975, Hesse, 1980, Lather, 1986a, 1986b; Patton, 2002) to a post-positivist belief that there is no neutral research (Hall, 1975; Reason & Rowan, 1981).

Post-structural thinking is that because of the complexities of human experience, and because scientific knowledge (especially in the human sciences) can never be free from social construction, there can be neither "the truth", [nor] "a truth" (Rich, 1979, p. 87). The notion of truth raises questions about any and all qualitative discursive research findings because of the multiplicity of possible provisional truths and falsehoods which may arise during its course, and limitations of interpretation. In post-structural discourse analysis, meaning for the speakers is not fixed, but constructed in specific situations

through particular inter-subjective encounters. Alternative interpretations of text are likely to be viable (Grbich, 2004; Crowe, 1998, Lather, 2006). As Frosh and Young (2008) noted, “No interpretation is sacred, there is no full and absolute truth; but some are more reasonable and persuasive than others on theoretical grounds but also in terms of their logic and productivity, the implications and conclusions to which they lead” (p. 118). Giddings and Grant (2009) therefore recommended the term ‘validation’ rather than rigour, and ‘validation strategies’ as the processes by which to address the issue of quality in post-positivist and post-structural research.

### **The Trustworthiness of Data**

In more abstracted modes of data interpretation, such as Foucauldian discourse analysis, processes must be adopted to ensure that the interpretation of the researcher and the conclusions made are credible and ‘trustworthy’ – a term coined by Guba and Lincoln (1981). Lincoln and Guba (1985) posited that the trustworthiness of the researcher and the research study are critical to evaluating its worth. To that end, they developed four concepts and techniques for the obtaining and defining of trustworthy data - credibility, transferability, dependability, and confirmability, all of which I needed to consider with regard to the relevance and validation of my study. As Guba and Lincoln (1981) stated, “relevance without rigor is no better than rigor without relevance” (p. 65). For example, as much as possible, I needed to have confidence in the credibility of my findings. I also needed to consider whether my findings might be applicable to other settings, and if they might be consistent and able to be repeated in similar settings. By confirmability, Lincoln and Guba (1985) meant a degree of neutrality or the extent to which the findings of a study were shaped by the respondents and not by researcher bias, motivation or interest. This involves the undertaking of reflexivity by the researcher. The validating of the research is seen as “an interactive, dialogic logic” (Reason & Rowan, 1981, p.240), through the use of self-corrective techniques that check the credibility of their data, and “minimise the distorting effect of personal bias upon the logic of evidence” (Kamarovsky, 1981, p.6). I will now describe the strategies I employed to validate my methods and my attempts to meet Guba and Lincoln’s evaluative criteria for trustworthiness.

### **Credibility – Confidence in My Findings**

Koch and Harrington (1998) stated that readers of research can only read what has been written by the researcher about what occurred during the research process and the



findings thereof, and it is then up to the reader to decide whether those findings are credible. However, responsibility for the credibility of one's research findings lies firmly with the researcher, and Guba and Lincoln (1981) provided some techniques by which I attempted to achieve this. They advocated a 'prolonged engagement' with the participants. I interpreted this to mean spending an extended time with my participants, not in a face-to-face way, but rather with the corpus of their statements until I was satisfied that data saturation had been achieved (Mason, 2010). This process allowed me to continuously monitor the range of my material, and to keep analysing my data until no new information was apparent.

Along with prolonged engagement Guba and Lincoln (1981) recommended a 'persistent observation' of the phenomenon being studied, in this case, breast cancer. This technique of rigour assisted me in attempting to ensure that the most relevant characteristics and elements of my research topic and questions were focussed on in detail, rather than pursuing unrelated factors. I attempted to establish consistency in my data, by triangulating or validating each piece of information against others. For me, triangulation meant the use of the two sources of data from the interviews with the women and with the health professionals. It was my way of ensuring the validity of my findings through their comprehensiveness and convergence of patterns (internal agreement). Using Guba and Lincoln's (1981) triangulating technique of 'negative case analysis' to overcome the potential for me to settle too quickly on patterns or interpretations of the interviews, I plotted the data on my Interpretive Grids (refer Table 2). The grids served as a mechanism for unbiased and consistent analysis.

Another important validation strategy is accountability for the credibility of one's work. This is supported through the technique of peer debriefing or expert critique, and involves the researcher asking others to examine the data and confirm the decision-making processes and conclusions made. To meet this criterion, I presented my work on a regular basis to my university supervisors, using them as a 'mirror' or 'devil's advocate' (Guba & Lincoln, 1981) to reflect my responses to the research process. During these sessions, they assisted me to recognise and understand any influence as the researcher I might have had in the interpretation of my data. They also proposed alternative interpretations of the data to mine.

The sending back of an individual participant's transcript for correction, and verification that the content accurately represented what they had said during an interview is another

technique to validate the accuracy, interpretation and analysis of the data. This is a form of member checking as advocated by Guba and Lincoln (1981), Lincoln and Guba, (1985), and Morse et al., (2002). Member checking is also “an important way of showing respect to the participants” of a research project (Liamputtong, 2007, p. 61). While most of my participants engaged in this process, there were some who refused, saying that the re-reading of scripts might “re-open old wounds” (women), or were “a burden of time” (health professionals). All of the participants indicated their trust in me that the research process I had undertaken would accurately reflect their accounts. However, as a post-structural researcher, and as argued in Chapter Two, I recognised that there were multiple truths in the participants’ accounts, and the subjectivities that emerged were fragmentary and contradictory. To that end there was the potential for my participants to disagree with my findings, and my interpretations could only be partial and incomplete.

Overall, I believe that through the application of the validation strategies described above, I addressed issues of the credibility of my research to the best of my ability. Following Guba and Lincoln’s evaluative criteria, I also needed to attend to the extent to which my findings could be applied to other settings.

### **Transferability – Applicability to other Contexts**

The relevance of a study is further established by its contribution to a current body of knowledge through its findings’ transferability to or ‘fit’ with similar settings. Geertz (1973) and Lincoln and Guba (1985) advocated that the best technique for establishing the trustworthiness of the transferability of findings to other contexts was through ‘thick description’. By describing a phenomenon in sufficient detail, rather than superficially, the researcher can start to evaluate the extent to which the conclusions drawn are transferable to other times, settings, situations, and people. Perakyla (1997) believed that the ‘possibility’ of the transferability of findings to other settings was a more useful concept when considering the transferability of findings. While I made every effort to make explicit the patterns of social relationships in the accounts of the experience of breast cancer by the women and health professionals and put them in context (Holloway, 1997), the contradictory nature of my findings meant that there could be no direct transferability (Willig & Stainton-Rogers, 2008). I could only consider that there was a *possibility* my findings were applicable to other populations of women and health professionals, and sites of practice.

### **Dependability and Confirmability**

In order to monitor the consistency of my research approach, I endeavoured to have an audit trail, or 'decision trail', as advocated by Koch (2006). This meant keeping a record of the research steps I took from the start of my study to the analyses and reporting of my findings. My reason for using an audit trail was to help me keep track of the changes which emerged through the iterative processes of analysing the interview data, and as a documented justification for the decisions I made which altered the content of the findings of the study (Lincoln & Guba, 1985). The material I included for audit were all of the interview transcriptions, my visual mind-mapping and analyses which I had plotted on poster-paper, my summaries, process and supervision notes, and personal reflexive notes. This paper trail provided me with a way to retro-actively assess (Malterud, 2001) the processes and manner of my research as it progressed. This became very pertinent in the identification and inclusion of the dominant discourses, and the decision to exclude those that were less dominant (Given, 2008).

### **Neutrality, Reflexivity/Self-reflection**

In the preceding sections I have provided a self-critical account of how I attempted to meet key evaluative criteria for the rigorous scope, content and credibility of my study. As a post-structural discourse analyst, I could not assert complete objectivity to the ways that I interacted and interpreted the texts. I will now describe how I considered my own influences and bias, and challenged my subjectivity as researcher (Grbich, 1999). Self-reflection or self-reflexivity is an especially critical aspect of conducting post-structural discourse analytic research, particularly in the social sciences, because it draws specific attention to the subject position of the researcher (Foucault, 1982a). The researcher acts both as a listener and interpreter of the data provided by the participant, and in order to credibly interpret that account, must make explicit their position in relation to the phenomenon being studied (Giddings & Grant, 2009).

The reflexive nature of Foucauldian-inspired post-structural discourse analysis means that 'human nature' can have a significant impact on the construction of the researcher's own subjectivity (Lincoln & Guba, 1985). Assumptions and self-knowledge or ways of understanding our own experiences and the experiences of others, are those that are most prevalent in the culture in which we are situated. Self-reflexivity is a validation strategy by which the researcher explores "the ways in which they themselves, in terms of their experience and prior assumptions, and the theoretical and methodological

processes they have chosen, shape the data collection and analysis” (Giddings & Grant, 2009, p. 128). Reflexivity is, as Haggerty (2003) writes, “a performance that positions the author in relationship to the field, the act of research, writing and the production of knowledge more generally.” (p. 58). As a researcher I was aware that I had created the conditions under which a thoughtful, I hoped, interview with my participants took place, using a ‘shared understanding’ model advocated by Franklin (1997). I also needed to consider that the interview, or confessional, as Foucault (1978) perceived it, was an analytic resource, with “its obscure familiarity and its general baseness” (p.62).

In order to meet the criterion of self-reflection, I made explicit at the beginning of my study my pre-understandings about breast cancer, including my beliefs, values and personal biases, which I described in Chapter One, and which I reiterate in the section below. Further to that, I re-scrutinised my data to locate those pre-understandings.

### **My Theoretical Position and Social Locations**

The person of me as ‘researcher’ was clearly implicated in the construction of a knowledge and power relationship within the interchanges between the participants and me. I had to be clear about the determining characteristics of those interchanges, including what I as the researcher brought to them. This was a critical factor in my evaluation of the credibility of my research findings. Qualitative researchers often draw upon their own experiences as a resource during their research (Denzin & Lincoln, 2005; Willig, 2001), and because the researcher is the primary data collection instrument or research tool, it is important that he or she clarifies his or her role within the research process and acknowledges his or her biases. Because my interviewing and the reading of transcripts were not neutral processes, it was important that I identified my relationship to the interviews and the texts (Arber, 2006). My position was post-structuralist in terms of my theoretical perspective, and female, New Zealand European, psychologist and teacher, and having personally had breast cancer, in terms of my social locations.

Because it is in the nature of the qualitative research enterprise to explore the deeper elements of social action, and because qualitative research is itself social action, the relationship between me as the researcher and the participants was an issue which inevitably pervaded all aspects of my study. The issue of personal reflexivity was one that I constantly had to keep in mind because of the need for me to be aware of how as a researcher, my values and beliefs could shape the construction of meaning during the

research process. When developing the interview guiding questions for example, or when conducting the interviews and analysing the data, I was ever mindful that my research approach could never be truly objective, neutral or value-free (Oliver et al., 2005). I needed to be able to recognise and acknowledge the transferability or the passing of any affective attitudes developed by me as the researcher, and as a woman, a psychologist and past cancer patient to the women and the health professionals (Morse & Field, 1995).

When developing the interview guiding questions, or when conducting the interviews and analysing the data, I tried always to be mindful of my purpose, processes and interpretations, knowing that my research approach could never be truly objective, neutral or value-free (Holliday, 2007; Oliver et al., 2005). There was always the potential for my views to dominate my engagement with the participants and/or the texts (de Laine, 2000). As such it was necessary for me to continually question my own subjectivity as researcher in relation to my pre-conceptions, motivations, relationships and my own ways of seeing the breast cancer experience.

Addressing subjectivity and reflexivity is a rather ambiguous task for the researcher, who must integrate being both an individual and a researcher. Subjectivity influences the research process, and I needed to be clear about my process of reflexivity through my awareness of the emotional impact on me in my roles of interviewer, listener, observer and discourse analyst. There are many phenomena within specific cultural and social contexts that are 'sensitive' (McCosker et al., 2001). They may be defined as 'sensitive' if they are private, stressful or sacred, and their discussion tends to generate emotional responses which should be acknowledged as influencing the study, especially as they may provide insight into dimensions or findings not previously anticipated by the researcher. Breast cancer is one such topic.

In response to the 'sensitive' nature of some research, Ethics Committees act as gatekeepers during the research process to protect individuals and/or groups who form the sample from harm, however these are not the only participants affected by the research. In addition to myself as researcher, my transcriptionist, supervisors and readers of my study were also placed at emotional risk, because they were exposed to experiences of the participants' lives which included graphic description of disturbing, heart rending and frightening events. These experiences can be novel and shocking to people, and there can be parallels found in one's own life. Frequent and regular

discussions or debriefings with my transcriptionist and supervisors helped to identify, respond to and minimise this risk as it arose for them during the research process. In order to take care of myself I used as much as possible some of the strategies recommended for coping with emotional and psychological distress created by the content of the interviews (McCosker et al., 2001). Given that time for study was restricted, I limited the interviews to one per week, arranged for someone else to undertake the transcription of data, listened to no more than one hour of interview tapes without a break or change of activities, did not read for the literature reviews about breast cancer on the same day as I conducted any interviews, and debriefed with a trusted colleague. The participants were aware that debriefings would take place and with whom, and it was made clear that the discussion would include reactions to the material and content. The strategies were used as the need for them arose, rather than by my using pre-planned strategies for facilitating my psychological and emotional safety (McCosker et al., 2001).

As soon as possible after each interview, I took structured notes about my engagement in the interview process. I did this for three reasons – (1) as an effort to remain in continuous dialogue with the context of the research questions (Guba & Lincoln's 1981 prolonged engagement and persistent observation); (2) in order to help me reflect on the way and manner in which I conducted the interview (reflexivity of process), and my spoken and unspoken reactions to it (self-reflexivity); and (3) as a record of key decisions made during the research process (an audit trail of dependability and confirmability). These notes provided me with a self-reflective record of analytically useful information by which I could isolate my personal biases and experiences during the interviews.

### **Authenticity and 'Situated Trustworthiness'**

Guba and Lincoln (1989, 1994), extending the notion of credibility beyond merely presenting a sophisticated but temporary consensus of views about what is to be considered true, developed a fifth criterion for the validation of research – authenticity. In their view, the authenticity of the research relates to how it enlarges personal constructions of the object of study, and improves the understanding of others. The authenticity of a study relates to the fairness in which it faithfully captures the lived experiences of people (Guba & Lincoln, 1994). There are always concerns about the accurate re-presenting of information obtained from study participants. This information operates through subjective language and constructs identities, and so while conducting

my analyses I was constantly mindful of who was being represented in the interview, and how.

Questions of ‘situated’ trustworthiness (Giddings & Grant, 2009) are important considerations in post-structural discourse analysis because large amounts of data are generated, and there is a danger of being over-rigorous (Sandelowski, 1993), and of limiting analysis to simple descriptive reports. The purpose of my research was not to have a large representative sample which would provide a wide overview of the accounts of many, but rather to explore how constructions came to be shaped, perpetuated and legitimised by my small sample groups through their individual use of language, and their positioning in the discourses by which they constructed breast cancer.

### **Catalytic Validity**

The last of Guba and Lincoln’s (1989, 1994) components of tactical authenticity deemed necessary for valid research, and which I thought particularly relevant to my study, encompassed matters of enrichment, education and empowerment. In my attempt to meet this criterion I drew mostly on Lather’s (1986a, 1986b, 2006) concept of catalytic validity.

Lather (1986a, 1986b) talked of the catalytic validity of one’s research. By this she meant did the research change the lives of any-one? Because of my study topic, I felt that this was an important question for me to consider. Lather (1986a) believed that “social science research should have ... empowering functions for the researched”... by .... “knowing reality in order to better transform it” (p. 67). Freire (1973) termed this the ‘conscientisation’ of respondents by their gaining of self-understanding and self-determination through participation in the research project. As mentioned earlier, there can be different interpretations of meaning in the data by the researcher and the researched. Indeed, critical social theory, especially in feminist and gender research, suggests that individuals may not understand the deeper, structural significance of their personal experiences, which in turn can contribute to their unequal positioning in society (Giddings & Grant, 2009; Ridgeway, 2011).

Post-structural discourse analysis strengthens different discourses and opens up spaces for study participants to draw on these different discourses. With hopes for my study of providing some insight into the assumptions made about the subjectivities of women and health professionals when related to breast cancer, the ways that I could see to

advance this knowledge were to provide a summary of my findings to all my participants (an ethical practice required by the two Ethics Committees who approved my study), and to disseminate my research through journal articles and presentations to interest groups.

In the preceding sections of this chapter I have described my processes for ensuring that my research was based on good science and complied with international qualitative and post-structuralist best practice. All research involving human participants must however, also meet high ethical standards. I now describe the ethical considerations for my study.

### **Ethical Considerations**

Breast cancer is a highly sensitive topic involving at least one vulnerable group within our society. Conducting research in this area involved emotional, psychological, ethical and professional risks for both the participants and for me as researcher. There was a critical need therefore, for me to employ stringent ethical and supportive strategies in order to address issues of informed consent, confidentiality and anonymity, and to minimise harm to all involved (de Laine, 2000; Lee-Treweek & Linkogle, 2000; Liamputtong, 2007; Liamputtong & Ezzy, 2005; Morse, 2002; Renzetti & Lee, 1993). In the following sections I outline the ethical issues pertinent to my research and the ways in which I attempted to address them.

### **Ethics Committees' Approval**

One of my first responsibilities when embarking on this project was to obtain formal ethics approval for the research study. I gained ethics approval from two committees: the New Zealand Northern Y Regional Health and Disability Ethics Committee (Appendix A) and the Auckland University of Technology's Ethics Committee (AUTECH) (Appendix B). The approval of the latter was necessary because of the inclusion of registered health professionals.

### **Informed Consent**

Once participants had agreed to take part, I met with each of them individually and talked about the study. At this time I also talked through with them the relevant *Participant Information Sheet* (Appendices C and D) which had previously been given to them by the Breast Care Nursing Co-ordinator. In order to avoid a sense of coercion, or any assumption that in indicating interest they had committed themselves to taking



part, I had used the wording “invited to participate” in the Information Sheet. The *Participant Information Sheet* contained details of the research and what involvement was expected of the participants. It stated their rights including that they should feel under no obligation to participate, had the right to refuse, could withdraw at any time and would not be contacted again by the researcher. The anticipated benefits and risks of participating were provided, as was the expected length of time the interview would take. I hoped that the *Participant Information Sheets* reflected adequately enough my attempts to uphold the principles of autonomy and respect for my participants.

Before the interview began, I also obtained the participant’s signed consent on the *Consent Form* (Appendix E), and asked if there was any further information about the study that she or he needed. Assurances that they had the right to refuse to answer any question, that the voice recorder would be turned off, any sections of the recorded interview deleted, or the interview terminated at any time were also reiterated.

### **Confidentiality**

As described earlier, as I completed each interview, I assigned each participant a pseudonym by which they would be known in the research. I chose the pseudonym rather than have the participants choose their own. This was so that there was something representative (known only to me) in the name I gave them that helped me to identify each individual during the complex process of analysing the data. At the time of transcription the real name was deleted and the pseudonym added. During transcription any further characteristics that might identify the participants to outside readers were deleted or changed. Completed transcripts were returned to the participants for checking that their identity and their accounts had been adequately protected. The names of the participants, digital voice recorder and transcript hard copies, field notes and computer copies were kept in a locked cabinet in a secured site which was not in my home, my place of employment, or the university. These are to be held in such a manner for a period of six years after the completion of the study, and then erased, and hardcopies shredded and destroyed. Under the ethical guidelines of the two Ethics Committees that approved my research, I was also required to protect the access password to the computer on which the interviews were transcribed. I did this by using only one personal computer for the full course of the study, the password to which was known only to me.

The transcriptionist employed to transcribe the interview recordings was required to sign a *Confidentiality Agreement* (Appendix F) stating that confidentiality would be maintained.

### **Emotional Support for the Participants**

Because of the sensitive nature of my research topic, I was aware of the risk that participating in the research could stir up emotions in the participants. Indeed, there were occasions when some of the women became tearful when recounting their experiences. Some of the health professionals too, exhibited emotional responses in the interviews. As a respectful and considerate interviewer and researcher I took an empathetic approach of support, and as described earlier, reassured the participants that the interview could be ended at any time, or stopped and resumed at a later date. I also gauged the emotionality of the situation as the interview progressed, with the intention of making the decision myself to turn the digital-recorder off. (As it happened, none of these actions was necessary).

As an extra support, the availability of professional counselling through the university's counselling services was made known to the participants. This was described and offered in the *Participant Information Sheets* (Appendices C and D). To my knowledge, none of the participants accessed this.

### **Openness and Accountability**

In terms of openness and accountability, there were some occasions when I shared my research process and basic findings with individual GPs, practice nurses, and a number of other interested women and men who had not taken part in the study. In addition, about every year over the eight years of the course of this research project I was required by my university to give an oral presentation of my work to key members of the Faculty.

Throughout my research process I endeavoured to apply the validation principles of authenticity and trustworthiness. By considering and addressing the issues set out above, I believe that the ways in which I applied my research methodology were my best efforts in being true to post-structuralism, and to the work of Foucault. I also have confidence that the steps or methods I took to conduct this study were principled, open and transparent, and that the findings were credible for the sample groups.

### **Treaty of Waitangi Considerations**

In Aotearoa New Zealand, ethics approval for all research conducted with humans requires that the three principles of the Treaty of Waitangi - Partnership, Participation and Protection - are reflected in the research process. While in fact, none of the women identified themselves as Maori, I needed to be mindful of the safety of all participants in the provision of opportunities for, and processes of recruiting, sites of interviews, and the presence of support person(s). I also needed to demonstrate an understanding and respect for the elements of spirituality and social codes in the Maori world that anything to do with the body is *tapu* (sacred), and of *whakamā* (shyness) when Maori participants are talking about their person to a non-Maori. To meet these requirements, I consulted with the University's Pro Vice Chancellor for Maori Advancement/Dean of the Faculty of Maori Development to ensure that my research process was culturally appropriate for Maori participants. I also consulted with a female Maori educational practitioner and Justice of the Peace, who acted as my immediate cultural advisor throughout the course of the study.

### **Summary**

This chapter made explicit the methodology and research methods I employed in this study. I provided the rationale for my choice of research approach as post-structural discourse analysis, drawing on Foucault, as the means of achieving my research goals. My attempts to meet the criteria for research validation were described. The process for the recruitment of participants was provided, as were the interview and transcription to text processes I used, and the steps I took to analyse the data. I described the ethical considerations and reflexive strategies I employed in order to minimise harm to the study participants and to myself as the researcher.

In the following chapter I present a review of the empirical literature in which the Foucauldian model of a history-of-the-present has been applied to studies of the medical discursive constructions of breast cancer.

## **CHAPTER FOUR: A FOUCAULDIAN MEDICAL HISTORY OF BREAST CANCER: A LITERATURE REVIEW**

### **Introduction**

The purpose of this chapter is to present and explicate the discourses identified in the breast cancer literature. The medical discourse is the dominant over-arching discourse evident regarding breast cancer in relation to symptomology, diagnosis and treatment. By using an archaeological and genealogical approach, I aim to show the different medical constructions of breast cancer at key historical periods, and the shifts and ruptures within the medical discourse of the causes and medical effects of breast cancer. This post-structuralist focus on medicine shows how the discipline of medicine has judged the 'truth' about breast cancer over time. My intention is to take Foucault's advice and not so much engage in the deconstruction of these dominant 'truths', but rather to delineate and analyse the complex contingencies that have made up the medical territory and medical experience of breast cancer. This chapter explores some of the conditions of possibility which have prevailed at given times for saying what is true about breast cancer. Essentially, this chapter is a literature review of the history of the present which considers the historical conditions that contributed to contemporary notions of breast cancer (Foucault, 1972).

For my electronic literature searches for this chapter and Chapter Five, I mostly used search engines google scholar, iMedisearch, PubMed and JSTOR. The key words were Foucault, breast cancer, medical history, gender, feminist research.

### **The Medical Discourse**

There has been much written about the history of breast cancer. While it has never been the only discourse regarding breast cancer, the medical archive is certainly the oldest, and the most abundant available for analysis. The close connection of treating and healing the body from ancient times with those who were literate, has ensured that contributions to the records have been many and varied (Donnelly, 1995; Martensen, 1994; Mukherjee, 2010; Olson, 2002; Yalom, 1997). This is an important factor in my argument – that it is medicine which has the longest, most established history of breast cancer, and it is medicine which makes many of these links to future constructions

(Mukherjee, 2010). For this chapter, I sourced mainly medical and history texts which cited ancient physicians and more recent cancer specialists, and contemporary oncology research literature.

The medical archive is very extensive, and provides multiple constructions of breast cancer as a discursive object. A review of the medical breast cancer archive serves to inform my own analysis by re-tracing those medical words, expressions and terminologies which have prevailed up to the present time, the reasons for their dominance, and their effects on speakers and listeners. These constructions have contributed to the one medical reality – how breast cancer is constructed medically today (Osborne, 1991). In other words, what we learn from this medical history illuminates what we regard now as the medical ‘truths’ about breast cancer, how we position ourselves within those ‘truths’, and how, to use Rose’s (1994) expression, “our [breast cancer] times could be different again” (p. 70).

My review of the literature of theories of disease and their relationship to the critical modalities of breast cancer, revealed that there are three discrete approaches to breast cancer within the medical archive that appear to have established the conditions for present day constructions of the disease. Consistent with Foucault’s methodology, they form four distinct chronological breaks within the medical archive that represent three different bodies of knowledge and power/knowledge systems. These can be broadly classified as:

1. The humoral theory, which dominated medical thinking from ancient times to the Renaissance.
2. The emergence of gross anatomy, which largely superseded humoral theory, and remained prominent from the Renaissance until the 1850s.
3. The cell theory and pathology which has dominated oncological thinking up to the present time.
4. The theory of multiple aetiology of causation, particularly environmental, genetic and immunological factors.

Each of these discrete approaches gave rise to particular scientific technologies that facilitated or contributed to the construction of breast cancer and which fed into the diagnostic and treatment repertoires favoured at the time. It is interesting to note the re-

emergence of the humoral theory (described more fully below) in some oncological thinking today (Lipmann, 2011; Travis, 2005), and the emergence of a bewildering variety of diagnoses, explanations of, and treatments for breast cancer which are impossible to capture in one category in the 21<sup>st</sup> century medical archive (McCarthy, 2005).

The earliest constructions of breast cancer are documented in the texts of ancient times. It is asserted that breast cancer is one of the oldest forms of cancer tumours in humans (Breasted, 1930). Documents from ancient Egypt and Nineveh, and sculptures of female torsos, some with retracted nipples and signs of diseased breasts as we interpret them today (Burnum, 1993), excavated from temples in Ancient Greece, indicate that breast cancer has been recognised as a discrete entity for centuries (Breasted, 1930; Haddow, 1936; Strouhal, 1976). The earliest record of what was probably human cancer was found in the Edwin Smith surgical papyrus, which dates from the Egyptian Pyramid Age (3000-2500 B.C.) In this treatise an anonymous surgeon describes eight cases of tumours or ulcers of the breast, and ancient medicine's general inability to effectively treat them. "If you examine a man presenting prominent swellings on his breast ... you should say concerning him 'This is a case of protuberant tumours I have to contend with. There is no treatment'" (Edwin Smith Papyrus, cited in Haddow, 1936, p. 1016). In one case however, treatment was attempted by cauterisation with a fire stick (anonymous 1930; Breasted, 1930). Writings dating from 2000 B.C. on cuneiform tablets from Assyria also mention the occurrence of signs characteristic of breast cancer as we know it today, and some from ancient China and India dated at about the same time record the existence of breast disease, and treatment with surgical excision, cauterisation and arsenic compounds. These archives confirm that cancer, as it is now called, was known to the ancients, with Greek physicians describing hard, 'cold' and 'painless' breast tumours as 'scirrhus', or dangerous precancerous growths that would 'usurpate' into cancer (anonymous, 1930; Baum, 1986; Breasted, 1930). A Foucauldian approach confirms that what medicine claims as the phenomenon we call today 'cancer' has a long history, and has legitimised and validated constructions of obvious, observable abnormalities of the breasts as being 'correctly' interpreted as cancer of the breast. Constructions of the causes of breast cancer have dramatically changed and shifted over time (Blaxter, 1983). The first of the constructions of the cause of breast cancer is well documented – the humors.

## **The Critical Modality of Humoral Constructions of Breast Cancer**

The most famous of Greek physicians, Hippocrates (460-370 B.C.), the oft-cited father of medicine and credited with placing medicine on a rational basis, described cancers of many body sites. Greek philosophers made few distinctions between the spiritual and temporal worlds, and Hippocrates postulated a 'humoral' theory for disease by making tangible connections between the cosmos and the body. That is, Air, Fire, Earth and Water were constructed as having biological counterparts in the body's four humours, or fluids, blood, phlegm, yellow bile (choler) and black bile (melancholy). Hippocrates believed that imbalances of fluids caused illness, and the body's production of vomit, diarrhoea, blood, mucous, jaundice and pus proved the link between excess fluids and poor health. Cancer, he believed, erupted from an excess of black bile (Hippocrates, c.400 B.C.- a,b,c; Porter, 1997).

### **The Discursive Object – Cancer the Crab**

It was the crab-like appearance, (a crab having ten spreading legs with two front claws or nippers with which to reach out and grasp) and feel, (a hard shell) of advanced tumours, that provoked Hippocrates to name cancer *karkinos*, thus giving it the genitive Latin name it has today, 'cancer' the 'crab'. Hippocrates, through his documented humoral theory of disease, is credited by some with providing the most enduring description of breast cancer, but in fact mentioned breast cancer only twice in his works, describing it as 'hard tumours within the breast' (Grmek, 1998), and like the earlier surgeon, advised no treatment (Temkin, 1991). From a Foucauldian lens, this can be seen as an example of conditions which are limited by the knowledge of the time, or by the possibility of other interpretations or constructions of abnormalities in the breast. Discursively constructed tumours are deemed incurable by a limited repertoire of treatment.

From *karkinos* evolved *carcinoma*, a medical term for malignant black bile tumours developing in the epithelial tissues. Introduced into mediaeval English in the 12<sup>th</sup> century as the Norman word *cancre*, it has been used in the present medical sense since the 17<sup>th</sup> century. The image of the crab as synonymous with cancer has lasted over time, with its some-time reputation for insidious wide invasion of the body. "Most often ... the sea fish called cancer ... gnaws away in all directions, and ... as it gnaws ... can walk sideways and backwards as well as forwards" (Pouchelle, 1990, p. 168). The Foucauldian analytic modality of the construction of tumours as untreatable killers with

an ability to spread throughout the body is a mode of appearance or imagery which arises in medical discourse, when a problem like breast cancer is symbolically named, and needs to be addressed (Deacon, 2000; Foucault, 1998). Despite ruptures in medical thinking over time, the image of the crab as a symbol of cancer has remained. It brought fear in the past, and while attitudes to death are ever-changing, cancer continues to be constructed as a threat to life, a discursive object which continues to conjure up images of death and dying.

### **The Earliest Constructions of Breast Cancer – A Systemic Disease**

Clarissimus Galen, a 2<sup>nd</sup> century AD Greek physician living in Rome, succeeded Hippocrates as the dean of Greek medicine. While he accepted humoral theory, Galen distinguished among different types of ‘unnatural growths’, and first situated breast cancer within a broader explanatory framework of disease (Galen, c.200A.D.; Grmek, 1998). His work is important in that he was one of the first to conceptualise breast cancer as a disease with the potential to break from a localised place and spread throughout the whole body (Martensen, 1994). Galen believed that some lesions were more dangerous than others and that the most deadly would eventually ulcerate through the skin, issue black bile and cause death. This is a second century dominant truth constructed and defined by physicians and other knowers of the body. Galen had little knowledge of the process by which cancer became systemic within the body, whereas modern medicine now constructs the process as lying within the vascular and lymphatic systems (Baum, 1986; 1992). That cancer is a systemic disease has had its own convoluted history of acceptance and non-acceptance within medicine, but lesions of the breast were very early on in history clearly associated with death or causing death (Mukherjee, 2010).

Humoral theory dominated Western medical and surgical thought from the 2<sup>nd</sup> century AD. Definitions found in many humoral treatises provide a picture of scirrhus of the breast which is indistinguishable from 21<sup>st</sup> century constructions, regardless of how it was classified and is classified today (Porter, 1997). “Cancer is the name of a tumour arising as it is thought from an adust or atrabilious Humor. It is round, unequally hard, and if not inflamed of a livid or brown colour, with exquisite pain: the Veins appear turgid in the Skin upon the surface of the Tumour” (Wiseman, 1676, Paper-back edition, 2011, p. 98).



These ancient explanations of health and disease were based upon notions of bodily equilibrium, predicating health as the balance of vital bodily forces or elements or humors. Such systems posited the body as existing in a constant state of flux, with bodily equilibrium strongly influenced by internal factors such as diet, environment, personality, predisposition and supernatural causes (Helman, 2001; Porter, 1997; Flemming, 2000). The humoral conception of the body posited it as inseparable from the environment around it, so the accepted thinking was that the air humans breathed, the food ingested, and the location in which they lived, were one and the same (Flemming, 2000). This made individuals vulnerable to environmental influences, and meant that the body itself was subject to change from a range of causes both internal and external (Jouanne, 1998). How differently signs of breast cancer were interpreted is reflected in Galen's thinking about the stagnation or coagulation of bodily fluids such as blood and milk. These fluids were viewed as forming obstructions and fermentations within the breast, detrimental to the physical and emotional functioning of the woman (Galen, c.200 A.D.; Siegel, 1973; Zimmerman, 2003). This construction, with gendered under-tones, was one of the most commonly implicated in the development of breast cancer over succeeding centuries.

From a Foucauldian view-point, the primacy of the humoral doctrine contributed greatly to the developing knowledge about breast cancer, because it not only provided some plausible explanation of the unknown interior of the human body, but also of the influence of heredity, regimen, climate, life experiences and the person's character in the development of illness. Many of these discursive practices are resurgent in contemporary medical contexts (Botteri, 2010; de Moulin, 1983; Jouanne, 1998; Mackinney, 1952; Nuttall, 1983; Porter, 1997), as many diseases are now attributed to deficiencies or excesses of certain enzymes, genes, trace elements and hormones. While the truth upon which theories of cancer have been based might seem to be the same, they are not, because there have been different understandings about what constitutes the body and processes. However, the association to modern thinking in some circles about the causes of breast cancer can be clearly seen (Helman, 2001).

### **The Paradox of the Inviolable Body**

The human body was inviolable for much of early Western medical history. Consequently, the Hippocratic healers did not generally practice surgery or dissection. However, medical history records a major paradox in approaches to addressing the problem of breast cancer. Despite Galenic notions of the sanctity of the intact body,

some physicians did perform surgery in the name of therapy (McVaugh, 1998; Ricci, 1978). While the Egyptians of the New Kingdom mostly believed that there was no treatment for breast cancer, or were unprepared to violate the body, the early Romans performed extensive surgery for cancer of the breast, including removal of the pectoral muscles. This ancient procedure was to be the fore-runner of the much later surgical truth of the radical and super-radical mastectomies of the early to mid-20<sup>th</sup> century.

Aetios, the 6<sup>th</sup> century court physician to Justinian 1 and Theodora, emperor and empress of Byzantium, eschewed all pharmacological treatments for breast cancer, and instead performed repeated incisions and cauterisations on Theodora's breast lump in order to remove all diseased breast tissue. When Theodora died in June 548 AD, in what was probably her mid-forties, Aetios knew that amputation of the tumour, or even the breast was not enough. For Aetios, breast cancer was a systemic disease, with the potential to spread rapidly, and to cause death (Ricci, 1978). In the 7<sup>th</sup> century, Paul of Aegina, an Alexandrian physician, described cancer as "... forming in most parts of the body, but more especially in the female uterus and breasts...." (quoted in Olson, 2002, p.13). Paul's particular gaze on the female body is an early reference to cancer being constructed as particularly a problem of the human female – a gendered construction of the 'risky female' (Lupton, 2012). Despite the Galenic bases of their doctrines, these ancient physicians constructed breast cancer as a systemic disease. They believed that amputation of the breast was not an effective cure because it did not address the fundamental problem as they saw it - the fluidity of the disease rather than a solid and stationary entity (Sebastian, 2000).

In a major rupture in medical history, Galen's widely read and disseminated scientific treatises were lost when the Roman Empire disintegrated, taking with them most of the written texts of the era's dominant medical knowledge. Some were preserved by learned scribes and physicians of the ancient Arab and Byzantine world, and more than a thousand years later, the late Middle Ages saw a return of both humoral and systemic theories. Physicians again treated women with breast cancer with bleedings and purging to relieve them of the tell-tale black bile. The 20<sup>th</sup> century technologies of medical 'truth' provided a surface of re-emergence for the now largely-accepted theory of breast cancer as a systemic-borne disease with local manifestations (Cantor, 2008).

Further contradictions in the cancer archive are exposed in the literature, such as the re-emergence of the inviolate body. Contrary to popular belief, the Church in the 1200s

never explicitly forbade dissection (Foucault, 1973; Porter, 1997). Christian doctrine considered the body subordinate to the soul, and the soul of a dying man was to be saved by a cleric rather than his body saved by a medical practitioner. However, by the late 13<sup>th</sup> century a complex set of spiritual, moral, legal and surgical norms had ultimately led to the sanctioning of dissection as a method of medical enquiry within medical schools, and to the development of theories derived from the study of gross pathological anatomy over the next three centuries up to the 1700s (Sebastian, 2000).

Through a Foucauldian lens, humoral theory fulfilled the disciplinary function described by him of according privileges to those with the knowledge and authority to provide explanations of disease (Foucault, 1973). Despite some competing discourses, the general principles of humoral theory were dominant, and many elements of the theory comprised the most persistent discourse of any found in the medical archive (McCarthy, 2005). Many 19<sup>th</sup> and 20<sup>th</sup> century historians later argued however, that the dominance of Galenic humoralism dogmatised medical thought, obstructed the understanding of breast cancer and contributed to a period of conservatism with regard to medical practice for nearly two millennia (Baum, 1992; Cantor, 2008; Haagensen, 1933; Virchow, 1962b; Wood, 1923). Yet, despite the competing discourses that existed in this episteme, the general principles of the humoral theory were dominant for a very long time. Medicine, as a means of asserting the legitimacy of humoral theory thus traces its history back to these ancient times.

### **The Critical Modality of Gross Anatomy – A Pathological Lens**

The study of critical modalities exposes the characteristic ways of thinking about disease at any one time. Contingency, or possibility, is always a significant factor in the shifts or ruptures in discursive constructions, not their inherent lack of truth (Foucault, 1970, 1972). The demise of the Galenic humoral theory heralded a significant shift of the gaze to a search for other constructions or explanations for breast cancer.

### **The Technology of Dissection**

The second major modality identified in the medical archive is the theories derived from the study of gross anatomy. These theories explored surgical consciousness in relation to breast cancer through investigations of the dead body by dissection from the late 13<sup>th</sup> century and over the next six centuries. The medical history of the 1700s provides examples of one of Foucault's key areas of interest – differences as opposed to similarities, or the notion of differentiation and deviance from the norm. It was at this

historical juncture that the classification of diseases, and related specialist disciplines began to emerge (Rose, 1994). With this shift came a change in the possessor of medical knowledge from Galenic physician to pathologic surgeon. This shift was eloquently recorded by French physician Pierre François Olive Rayer, who made important contributions to the fields of pathological anatomy, physiology and comparative pathology in the early 19<sup>th</sup> century. “An entirely new period for medicine has just begun in France ... analysis applied to the study of physiological phenomena, an enlightened taste for the writings of Antiquity, the union of medicine and surgery, and the organisation of the clinical schools have brought about an astonishing revolution that is characterised by progress in pathological anatomy” (Rayer, 1818 cited in Foucault, 1973, p. 124).

A key figure in the later stages of this period (early 19<sup>th</sup> century), was Italian anatomist and celebrated father of modern anatomical pathology, Giovanni Morgagni. Morgagni published the first systemic text book on morbid anatomy, in which he discussed breast tumours and also described the difference between the healthy and unhealthy body in relation to post-mortem findings (Haagensen, 1933; Sebastian, 2000). The body of knowledge of human anatomy, physiology and pathology that surgeons derived from their practices of formal dissection and internal surgery was to become enormous, and resulted in a medical, and more specifically, a surgical archive of multiple and competing theories of disease (Foucault, 1973), much of it advanced by French anatomist and physiologist Marie François Xavier Bichat and John Hunter, English surgeon and anatomist (de Moulin, 1983; Foucault, 1973; Haagensen, 1933; Haigh, 1984; McGrew & McGrew, 1985; Virchow, 1962b).

In England, John Hunter specialised in systematic post-mortem examinations. He did not accept humoral theories of disease, believing instead that truth was to be discovered with a scalpel on the dissection table (Qvist, 1981). This was the beginning of medical empiricism – the belief that medical knowledge stemmed from experience, learning or information acquired by medical observation or experimentation. Medicine now held the only truths about the body because bodies were irrefutably observable and measurable. With a shift in understanding that the church or state no longer required the body to be preserved intact, Hunter conducted hundreds of dissections of women who had died of breast cancer, and confirmed his hypothesis that cancer can spread through the lymphatic system (Olson, 2002).

These developments in human dissection began to focus attention back on to the lymphatic and vascular systems as sources of cancer. While some Galenic distinctions remained in force with regard to these bodily fluids, use of the term humor had largely disappeared, and been replaced with the words ‘fluids’, ‘lymph’ or body ‘juices’ (Porter, 1997). A Foucauldian perspective does not view this as the re-emergence of the earlier theories of breast cancer as a systemic disease, but rather that dissection offered another more visible and tangible way of seeing the body inside. Medical truth and knowledge through empiricism thus confirmed the links between disease and human physiology (Foucault, 1973).

Possibly Hunter’s greatest contribution in what has come to be known as the discipline of oncology, is that specialists treating breast cancer patients need to examine tissues near the tumour to determine whether the cancer has spread to nearby lymph nodes. His was the accepted theory in late 18<sup>th</sup> and early 19<sup>th</sup> century medical and surgical textbooks (Onuigbo, 1971), and it still stands today. The need for the medical gaze to be able to distinguish between benign and malignant tumours continued as a diagnostic challenge however. Furthermore, the idea that the study of the functioning of the healthy body which did not deviate from the norm was necessary in order to understand abnormal states, resulted in Hunter and others developing classifications of diseases according to their differences (Qvist, 1981).

### **The Emergence of the Doctrine of Tissues**

Traditional medical history proposes that the end of the 18<sup>th</sup> century witnessed an abrupt turning point in the understanding of disease. The advent of pathological anatomy is generally accepted in medical literature to have been led by Marie-François Xavier Bichat in France (Nafziger, 2002; Simmons, 2002). Despite working without a microscope (although the microscope had already been invented), he was the first to introduce the notion of tissues as distinct entities, and maintained that diseases attacked tissues rather than whole organs. In 1801, Bichat discussed the notion of cellular tissue in his book *Anatomie Generale*. This is what modern medicine credits as a defining or revolutionary moment in the history of medicine and surgery – the emergence of a body of knowledge constructed from the study of tissue, to be termed histology. For Foucauldian historians of the present however, the turn of the medical gaze to tissue is a rupture and a re-emergence because anatomical dissections had been occurring for at least three hundred years prior to this, but had discontinued to be prominent in medical

constructions and understandings of disease until this re-surfacing (de Moulin, 1983; Foucault, 1972).

Bichat and his colleagues gathered together the accumulated knowledge from centuries of anatomical dissection. In their so doing, the medical gaze shifted to the examination of increasingly minute pathological systems in the quest for new knowledge and explanations of disease, of which cancers of the breast were but one (Cantor, 1993; McCarthy, 2005). One of the most significant ruptures in medical thought which emerged from the work of Bichat and other anatomists and physiologists at this time was that tissue, unlike organs and other larger structures in the body, appeared to be capable of reproducing itself (Haigh, 1984). It was this construction of the integrative and reproductive nature of tissues that led to Bichat's theory of disease in which he postulated that different parts of the body might experience similar disease processes if they were made up of the same tissues (Cantor, 1993; Haigh, 1984; McCarthy, 2005). This emphasis on the similarity and difference in tissue structure obtained from the dissection of corpses, and on the observed differences in the anatomical features found in individuals who had died from certain diseases from those who had not, advanced the idea of the classification of disease (Foucault, 1973; Qvist, 1981). John Hunter, practising in the mid-18<sup>th</sup> century in England was an influential proponent of this idea. In the early 19<sup>th</sup> century (1812) French physician René Laennec, with an interest in cancerous tumours, theorised that the more dissimilar the growth to normal tissue, the more cancerous it was (Simmons, 2002). Leannec also invented the stethoscope in 1816, a progressive technology of surveillance by which the discipline of medicine could further legitimate its knowledge and disciplinary power through other readings of the inside of the body (Armstrong, 1994; Foucault, 1973).

The dominant medical discourse at this time contributed to a reluctance by practitioners to offer concrete definitions of cancer in their efforts to differentiate tissue types. Definitions were not able to confirm what exactly cancer was, but rather emphasised what it was not. Cancerous tissue did not resemble normal tissue – a biological construction of deviance from the norm that has persisted to this day (McGrew & McGrew, 1985; McCarthy, 2005). Despite the confusion regarding every aspect of disease causation in this period, there is some continuity in explanations of breast cancer aetiology, in that similar to humoral theory, it was attributed to local and systemic causes, or a combination of both (Baum, 1986). Now, diseases like breast cancer and the life of the patient could no longer be conceptually opposite; rather the one could act as

an epistemological surface for the emergence of the other. This form of medical gaze was not only on the form of tissues, how they were distributed and organised, but also on the ways that they interrelated with other tissues and systems of tissues in the states of health and illness (Foucault, 1973). Each living body was considered an organic unit beset by, and responsive to, the forces of the surrounding inorganic (physical and chemical) world (Cantor, 1993; McCarthy, 2005).

### **The Critical Modality of Microscopic Anatomy – The Doctrine of the Cell**

The third identifiable Foucauldian rupture in medicine's construction of cancer and its causes resulted from the narrowing of the medical gaze from grossness to minuteness. Conventional medical history credits the work, in the late 1830s, of Rudolph Virchow, German doctor, anthropologist, pathologist, pre-historian, biologist and politician, as cementing another truth in the medical sciences – the belief that the cell is the basic unit of life (Virchow, 1962a). By the middle of the 19<sup>th</sup> century, the development of histological staining methods had eliminated tumour classifications based on similarities and differences in tissues. Instead, tumours were classified according to cell type, and their normal and abnormal features (de Moulin, 1983). The cellular explanations of breast cancer that developed at this time were to have profound implications with regard to subsequent conceptions and treatments of breast cancer well into the 20<sup>th</sup> century (Cantor, 2008).

The ability of the microscope, described by Virchow as an 'instrument of reform', in assisting pathologists to distinguish between benign and malignant cells, was a major contribution with regard to the classification of disease, and to the monitoring of cancerous spread (McMenemey, 1967). 'True' cancers were differentiated from other tumours, lesions, cysts and ulcers. The difference between local and systemic spread was also understood, with benign growths being constructed as localised, encapsulated overgrowths, and malignancy as systemic spread through lymphatic and vascular channels.

The spread of cancerous cells was termed 'metastases' (from the Greek 'displacement') by French physician and gynaecologist Joseph-Claude Récamier in 1829, and has come to be medically accepted as the development of secondary malignant growths at a distance from the primary site) (Haagensen, 1933; Haigh, 1984). With a particular focus on breast cancer, American surgeon William Halsted (who was to develop and champion the Halsted Radical Mastectomy) and his followers assumed, following

Virchow, that cancer spread from its origin along the lymphatic channels to the lymph glands and nodes which they believed filtrated the mammary system. Once overflowed, the cancer cells flowed further into other regions of the body (Halsted, 1895). The construction of the metastatic nature of cancerous cells by surgeons became a critical medical truth, based in the emotion of fear. Both surgeon and patient alike, fear cancerous spread, and after treatment, its recurrence or 'relapse' (de Morgan, 1874; Grange et al, 2002).

The cellular thesis was not so much a revolution from a Foucauldian point of view, but a re-framing of the medical conceptions of cancer. Foucault's (1972) approach to the archaeology of knowledge showed that medicine has constructed and therefore treated the body differently at different times through its emerging different disciplines. These days, science and medicine construct the body in terms of genes, cells, tissues and organs, and treatments for vagrancies from the 'norm' are targeted at them accordingly. It is also a medical truth (before the recent advent of the sub-specialist discipline of psycho-oncology (Davison et al., 1994; Holland, 1998, 2010; McPherson et al., 2000; Welsch, 2009), that the body analysed for psycho-social distress remains a psycho-social object (Lupton, 1997). It is with the work of Bichat that the beginnings of the *social* problematisation of breast cancer, rather than the medical, started to emerge. A cancerous cellular tumour is a basic physiological fact across time and space, but the degree to which that tumour becomes a problem is very largely determined by not only the medical, but also the social contexts of those who claim it. This is the topic explored in the literature review in Chapter Five.

### **The Rise of Surveillance Technologies of Detection**

Foucauldian studies (Duschinsky & Rocha, 2012), and traditional history, show that at the beginning of the 19<sup>th</sup> century, care of the sick and treatment of most ailments was the domain of women. The family was still the centre of a largely domestic social and economic life, and it was women who applied handed down knowledge of medicinal herbs and folk traditions. Midwives and homeopaths dominated, but some professional medicine existed in cities or more urban areas, which was accessible only to an elite few. The era known as the Second Industrial Revolution, (also known as the Technological Revolution), was a phase of the larger Industrial Revolution in the period from the last half of the 19<sup>th</sup> century until World War I. Industrialisation affected medicine in many ways, and with the destruction of the traditional domestic economy, the distance between domestic and professional medicine widened even further.



Medicine relied much more on rigorous scientific knowledge, and the training of physicians became institutionalised (Armstrong, 1983, 1994; Foucault, 1973; Osborne, 1994; Rose, 1994; Zola, 1973).

### **The Institutional Gaze**

The emergence of the hospital as the crucial epoch in modern medical history is a complex phenomenon which has been firmly established by Foucault and others (Armstrong, 1983; Foucault, 1973; Nettleton, 1992; Osborne, 1991; Rose, 1994; Turner, 1992). This is what Foucault described as ‘the birth of the clinic’ (Foucault, 1973). The hospital allowed for the repetition of observations of constant phenomena in relation to breast cancer because of the large number and variants of cases, rather than those seen in surgeons’ rooms in private practice (Armstrong, 1995). In his discussion of enunciative modalities, Foucault developed the notion of the hospital as a site of constant, systematic and comparative observation of disease, which established the norms of diseases, and increased medicine’s knowledge of, and power over them (Foucault, 1972). Progressing the doctrines of tissue and the cell, the hospital domain became a neutral, standardised context - a surface of emergence that deepened understanding of breast cancer by its power to observe all variations of the disease as well as the similarities, in order to know it well and to know it best (Foucault, 1973).

Medical empiricism emerged in hospitals as the result of its ability to interpret what it considered other competing theories could not, and to develop and use its own language to justify those interpretations (Osborne, 1994). The discipline of medicine generally was able to develop its own language, or jargon, which described disease and tumours in consistent and precise ways by means of a systematic and unchanging vocabulary (Foucault, 1973). The accuracy and difficulty of medical language clearly defined the boundaries of the profession, and did it at the critical time in its history when the perceptual field and medical gaze extended its surveillance powers from the dead into the living body (Olson, 2002). There were two critical progressions in surgery that facilitated this surveillance of the body – the discovery and use of antiseptics and anaesthetics.

### **The Emergence of Asepsis and Anaesthesia**

The surgical gaze moved towards meeting the major challenge of addressing post-surgical infections, and of the anaesthetising of patients. As a result of the increasing dominance of surgery as a treatment for breast cancer, the number of mastectomies

performed increased; however, a number of women who survived the operation died in a few days or weeks as a result of the streptococci infection known as erysipelas, which had a specific meaning at the time. This tragic phenomenon was positioned within significant changes in medical thinking through time, as commonly accepted by medical historians. For example, miasmatic and germ theories of disease overlapped for a long period, even after the identification of specific micro-organisms and their relation to diseases. Similarly, antiseptic and aseptic approaches were distinctly different, often vehemently held, and problematic (Wood, B., personal communication, November 25, 2014). For example, Joseph Lister, a surgeon in Glasgow, believed that post-surgical infection occurred when an invisible, external entity (what he envisaged as a ‘vapour’ or ‘humor’) entered the incision site. When he learned of French chemist Louis Pasteur’s discovery of microbes, he started washing his hands, bandages, surgical instruments, and the relevant parts of the surgical patient’s body in carbolic acid, and performed the first antiseptic mastectomy at Massachusetts General Hospital in 1869 (Olson, 2002). Lister’s work with carbolic sprays was understood as antiseptics, whereas Lawson Tait’s work on preventing the presence of micro-organisms more generally in the clinical environment led to asepsis (Greenwood, 1998). It can be seen then, that Foucault’s notion of rupture did not quite fit with historians’ approaches to understanding such changes in medical thinking (Wood, B., personal communication, November 25, 2014).

In 1846, John Collins Warren and T.G. Morton at Massachusetts General Hospital in Boston first used inhaled sulphuric ether to keep a patient unconscious during a minor dental surgical procedure. News of this public demonstration of surgical anaesthesia quickly circulated the world, and the historic event is well documented in the surgical archive. Pioneering uses of ether were key factors in the medical and scientific pursuit now referred to as anaesthesiology, and facilitated the development of modern surgery. After the first demonstrations of general anaesthesia with nitrous oxide or ether, its use was rapidly adopted in Europe and the rest of the world. Interestingly however, there was some initial resistance from those who believed that it was ‘not moral’ to eliminate pain, particularly in childbirth. This gendered discursive practice was overcome when Queen Victoria’s physician administered chloroform to her to eliminate her birthing pains. Ether and chloroform subsequently became the drugs of choice, for both childbirth and surgical interventions, such as for breast cancer.

### **The Gross Anatomical Surveillance by X-Ray and the Microscopic Staging of Cells**

The emerging technology of the Industrial Revolution meant knowledge, and an increasing number of technologies, were developed and administered to better understand and overcome disease. This was achieved by the re-favouring of the ancient practices of manually touching, palpating, pulse-taking, smelling, and listening to the body (with Laennec's stethoscope) (de Moulin, 1983). The X-ray, discovered by Wilhelm Roentgen, was a key part in the empirical diagnosis of medical problems faster and with more accuracy. New factories were able to produce more sophisticated medical implements such as fine syringe needles and more powerful lenses for microscopes. Wars with France and in the Crimea in the mid-1850s led to improved surgical procedures and nursing care, and as communications developed, ideas could be exchanged more quickly.

The advent of the microscopic 'staging' systems of cancer cells contributed to the classification of women's risk of dying of breast cancer, and raised questions about the value of deeper and more extensive surgery. During the 1920s, some pathologists began to argue that breast cancer cells could be microscopically classified by degree of malignancy. Cells were classified as Class I, II or III depending on malignancy and aggressiveness, thus determining the likelihood of curability. In addition to pathological classification, German surgeons in the late 1900s had staged tumours anatomically according to how far they had spread, and thus the likelihood of long-term survival. Stage I disease was small tumours confined locally to the breast; Stage II disease was larger tumours with spread to the axillary lymph nodes under the arm; and Stage III disease was tumour involvement of the breast, the axilla and surrounding tissues. These classifications of the early 1900s have been only slightly refined to today's biometric system called STAGING-TNM in which T1-4 stands for tumour size in centimetres, ulceration or fixed to chest wall, N0-3 for nodes negative, positive, large or near collarbone and M0-1 for no or some metastasis (Sobin et al., 2009). This system is what medicine calls a communication aid in that it helps medical staff to plan treatment, is an indication of prognosis, assists in the evaluation of results of treatment, and enables facilities around the world to collate information more productively (Miller et al., 2000). It is also a common reference point for communication between doctors and with patients (Goodyear-Smith & Buetow, 2001; Leopold, 2000). As such, it is illustrative of the Foucauldian notion of how knowledge is fed through such systems and extended (Foucault, 1972; 1973; 1980).

The staging of tumours in the breast is a form of surveillance or medical scrutiny of women, gridded by norms of health – Foucault's (1973, 1977) grids of specification and normalisation. Women being investigated for breast cancer were now located within a new rationality in which security for each woman was to be minimised or maximised through the application of a calculus of cellular risk (Ewald, 1991). The development of cancerous tumours was something over which women felt that they had no control, but the notion of risk is expanded in the medical and public health campaigns' move to individuals taking responsibility for their own health (Bernstein, 1996; Foucault, 1984), exercising self-control and self-surveillance, or 'governing the risky self' (Armstrong, 1994; Greco, 1993; Foucault, 1982b; Lupton, 1993; Nettleton, 1997; Ogden, 1995; Turner, 1997). Cellular pathology thus provided a locus for another type of relationship between doctor and breast cancer patient, based on the biomedical model of medicine. When medicine was practised in the home, the patient was in a position to define and dictate the nature of her illness; hence the existence of a symptom-based medicine. But after the advent of the hospital and further, the establishment of the discipline of cellular pathology, the doctor's dominant role ensured the emergence of a medical discipline based on pathological cancerous lesions. Further, these variations from the norm were, in Foucauldian terms, inaccessible to the woman patient without medical interpretation. This correlation between the doctor-patient relationship and the form of disciplinary knowledge was not only important in the generation of greater medical knowledge and power, but it also functioned to maintain that particular relationship. Thus the deployment of a discipline based on pathology reinforced a relationship between doctor and patient which was dominated by the doctor. This typifies the nature of the doctor-patient relationship which has continued to the present time (Armstrong, 1994; Goodyear-Smith & Buetow, 2001; Leopold, 2000; Little et al., 1999). The change of setting where medical consultations and surgical operations took place, from the patient's bedroom or surgeon's office to public hospitals was the next major rupture in the medical history of breast cancer.

### **The Rise of Foucauldian Technologies of Health**

The development of hospitals coincided with the rise of surgery as a medical discipline, jealously guarded by surgeons, some of whom regarded the application of other theories and therapies to the field of cancer with suspicion. It is at this point that the emergence of self-protective, bordered disciplines and professions becomes evident (Rose, 1994). With sharper microscopic images and the advent of anaesthesia and X-ray, the

discipline of medicine could now perceive what was within the visible living body and chart disease without having to 'plunge into it' (Baum, 1986; Foucault, 1973). Over the next century, these procedures of reading the living body were developed into the modern-day multi-dimensional surveillance technologies of radiography, mammography, ultrasounds and thermo-imaging, and to the progression of analytic techniques where the living patient does not have to be constantly present (for example, blood tests, and sophisticated sectioned and stained histological specimens, tumour markers and staging systems) (Lock et al., 2000). A woman today, is not present when her pathological diagnosis is made. Paradoxically, the body can now be made totally abstract and theorised in contemporary health care by the surveillance techniques of reducing it to increasingly minute and isolated parts. These events were fore-runners of the technological and electronic inventions upon which modern medicine is now dependent for surveillance, measuring and reporting on deviations from the norm. Such surveillance tactics also serve to classify those at risk, and perpetuate the dominant discourse of risk within the disciplines of medicine and public health (Armstrong, 1995; Candlin & Candlin, 2002; Lupton, 1993, 1999a, 1999b; Nettleton, 1997; Robertson, 2000).

The early hospitals became simultaneously inclusive rather than exclusive, normalising, an outward looking facility rather than panoptic, a site of knowledge and 'a therapeutic instrument' (Osborne, 1991). This transformation of 18<sup>th</sup> century hospitals into 'curing machines' (Osborne, 1991), was a complex evolution involving shifts at many levels. Foucault's notion (1972) that that which is new comes about within a clearing or surface opened up by the connections between diverse elements and practices is well illustrated here. The increasing hospitalisation of the poor was certainly related to the processes of urbanisation and industrialisation (Rose, 1994). The collection or assemblage of sick people in a single institutional space under medical techniques of surveillance such as observation, notation and record-taking, enabled illness to be normalised (Foucault, 2000; Hacking, 1991). For example, doctors could now observe an entire series of instances of a particular condition such as breast cancer, observe similarities and differences between symptoms in different women at any one time and over time. As Rose (1994) put it, "This provided the conditions for a statisticalisation and normalisation of diseases: a new classificatory system which would reduce the uncertainty inherent in medical diagnosis by the location of the individual facts of any particular case within a field structured by norms. A symptom was now to become

intelligible because it was a fact that could be assessed in terms of its convergence or divergence from such norms” (p.60).

Foucault uses the example of the hospital to illustrate the nature of certain general disciplinary technologies. One of the most significant is that the medical discipline developed and acquired its own language. But the hospital also illustrates two other of Foucault’s lines of enquiry as described by Rose (1994) – the divisive practices of hospitals of separating the sick individual from his or her personhood by the patient being constructed and named as ‘a case’, and the medical expertise within hospitals becoming the main institutional apparatus of medical reason. Like law and theology, medicine became a specialist area and a profession, but the gendered discourse of professional medical societies denied women membership. Consequently, medicine at this time became the exclusive domain of men (Olson, 2002). This patriarchy in the medical world is a practice which has persisted to a greater or lesser extent to this day (Bartky, 1988; Turner, 1987).

### **The Repertoire of Medical Treatment for Breast Cancer**

Favoured treatments for breast cancer have arisen, fallen back and been repeated many times in the long history of the disease, as the result of accepted knowledge and thus truths about its cause (Foucault, 1972; 1973). For over two thousand years, breast cancer had been viewed as a systemic disease, a malady indicative of fundamental flaws in the body, and involving the whole body, not just the appendage of the breast. With the abandoning of systemic theories, local and cellular processes again became preferred. Surgeons found that cancer would often return, despite wide excision of local tumours. The explanation was that due to the fundamentally microscopic nature of the cells that caused cancer, total excision of the original tumour might not be possible, and that recurrence occurred because cancerous cells remained. The emergent medical logic was that breast cancer was a disorder which, if diagnosed and eradicated in time, could be cured by the surgeon’s scalpel, and the sooner the better. Delay in treatment (whether by patient or by health professionals or systems) only gave the tumour time to spread (Olson, 2002, 2009).

### **The Discipline of Surgery**

The one primary treatment for cancer which has stood the test of time is the surgical removal of the cancerous tumour and surrounding cancerous tissue. While a generally-accepted single theory of the cause of breast cancer continued to stimulate debate,

surgeons' certainty about mastectomy, or amputation of the breast as the only reasonable treatment increased. German surgeons had called for mastectomies since the early 1600s and had developed specialised instruments for the operation including forceps, fishhook lances, ropes and hot irons for cauterising the wound. The French surgeons followed, believing only the scalpel could cure cancer, and rejecting other treatments such as chemicals, poultices, powders, creams and salves or internal pharmacological remedies. American surgeon Benjamin Rush, who had remained open-minded about the possibilities of finding medicinal treatments in nature (Butterfield, 1951) finally concluded in 1784, "I am disposed to believe that there does not exist in the vegetable kingdom an antidote to cancers ... The knife should always be preferred to the caustic" (Olson 2002, p. 36). Because all known non-surgical treatments had been deemed by medicine to have failed, the surgical truth in effecting a successful cure was to cut the cancerous tumour and surrounding tissue out. Removing as much cancerous tissue as possible seemed to provide the only realistic possibility of preventing recurrence, and a virtual death sentence. By the mid-19<sup>th</sup> century most physicians believed that surgery was 'the only hope'. Mastectomies were becoming well known at the time in Philadelphia, Boston and New York, with the operations believed to have achieved a cure in women who lived to old age. The facilitation of surgery as the most effective method by which to treat breast cancer strengthened medical constructions of bodily organs as being problematic when diseased, and but also reinforced the depersonalisation of the body through surgically operating on it (Collins, 1994).

### **The Radical and Super Radical Mastectomy**

Asepsis, anaesthetic and cellular pathology made radical mastectomies possible in theory, and the pre-anaesthesia surgery of the past, based so much on the speed of the surgeon, gave way to deliberate precision in which the surgeon excised diseased tissue so that normal physiological processes could be restored. But there were issues of access by women, because in the early 1880s women usually did not visit physicians in the early stages of the disease. Many procrastinated, hoping that the lump was not a cancer. As mentioned earlier, the operation which came to be known as the Halsted Radical Mastectomy was named after William Stewart Halsted, head surgeon of the John Hopkins University Hospital, who performed it first in 1882. The procedure involved the surgical removal of the entire breast, axillary lymph nodes and both underlying chest muscles in a single en bloc procedure. Even today mastectomy is still

called radical surgery, and is often heard in the expression of the gratefully spared patient, “I did not have to have radical surgery”.

The prevailing logic of malignancy and metastasis was now that breast cancer did not spread through the bloodstream, but along major tissue lines and in the lymphatic system. Lymph nodes, Halsted believed (like Rudolf Virchow in 1847 and William S. Handley in 1906) served as barriers to tumour spread, but there was always the danger that they would break out and spread to distant sites. This theory of ‘contiguous’ development of metastases spreading from one source was articulated by Halsted and it thus became known as the Halsted theory, Halsted hypothesis, Halsted paradigm, Halsted model, or ‘Halstedian view’ (Bartlett et al., 2011; De Vita, 2008; Lewison, 1972; Olson, 2002).

At this rupture in the medical history of breast cancer, there were some significant changes in medical discourse and discursive practices. The Halsted Radical Mastectomy offered breast cancer patients and surgeons an alternative choice and possibility of a cure. Up to now, this had not been the case. In 1895, Halsted reported, “Most of us have heard our teachers in surgery admit that they have never cured a cancer of the breast. ... We rarely meet ... a physician or surgeon who can testify to a single instance of a positive cure of breast cancer” (Halsted, 1895, quoted in Olson, 2002, p. 61).

From 1890 to 1910, Halsted and his students and colleagues performed thousands of radical mastectomies. Learning from the information they obtained from these procedures allowed them to experiment further in determining the seriousness of a tumour by staging it in order to make a prognosis. This is an example of Foucault’s (1972; 1973) grids of specification - the systems by which the different types of tissues and cells were able to be compared, contrasted and classified as objects of the pathological discourse. Their conclusion was simple and clear - women who received a radical mastectomy before the tumour spread to regional lymph nodes had excellent odds. Women who delayed treatment were ‘doomed’ (Lewison, 1972, p. 276).

By 1907 Halsted reported, “Women are presenting themselves more promptly for examination, realising that a cure of breast cancer is not only possible, but if operated upon early, quite probable. Hence the surgeon is seeing smaller, still smaller tumours, cancers which give not one of the cardinal signs” (Halsted, 1907, quoted in Olson, 2002, p. 63).



The Halsted Radical Mastectomy remained the treatment of choice for breast cancer for the next sixty years (Brooks & Daniel, 1940), up to the mid-1940s, and was performed on thousands of women, including patients in New Zealand (of whom my maternal grand-mother was one. For her, however, radical mastectomy did not affect a cure). The risk of the radical mastectomy remained however, and some patients did not survive the operation. Other women avoided it because the operation would leave them permanently disfigured, with side effects that would last for the rest of their lives. Still, the Halsted radical mastectomy became the most common major surgical procedure in the world (Fisher & Gebhardt, 1978), and considerably altered medical thinking about breast cancer treatment. It also gave patients hope, and inspired a new public health movement in the push for early detection (Olson, 2002).

Early into the 20<sup>th</sup> century no consensus about metastasis had emerged, and remnants of the ancient humoral theory of systemic tumours continued to survive. Recurrences of cancer after mastectomy re-emphasised the concept of spread. Because it was believed that tumour cells had spread beyond the tissues removed in the original mastectomy, some surgeons advocated even more extensive surgery. Thus, more radical surgery became the logical extension of the theory, and the surgical technique which became known as the super radical mastectomy became a discursive practice. The Halsted technique was replaced, and the discipline of surgical oncology was lifted to a new level.

The super radical mastectomy was pioneered by Jerome Urban, a surgical oncologist at Memorial Sloan-Kettering Cancer Centre, New York, who extended the Halsted radical mastectomy to remove the breast, the axillary nodes, chest muscles and the internal mammary nodes in a single procedure. His logic reflects a shift in the medical gaze: “We should increase our salvage of early operable cases over the present results obtained with the usual radical mastectomy, which completely neglects the internal mammary lymphatic chain” (Jerome Urban, 1952, quoted in Lerner, 2001 p. 129). Furthermore, the dominance of the cellular and metastatic theories, and followers of Bichat’s work, argued that bilateral total mastectomy was warranted in even the smallest unilateral tumours, to check the growth before it appeared in the other breast. The super radical mastectomy was described by some surgeons however, as “fore-quarter amputation”, and as “the medicine of mutilation” (Olson, 2002, p. 65).

## **The Extended Medical Catalogue of Causes of and Treatments for Breast Cancer – Mid-20<sup>th</sup> Century**

Developing explanations about the nature or characteristics of breast cancer led to further advocacies for particular treatment approaches. During the 1930s and 1940s, radiotherapy evolved and became more powerful. In the wake of World War II, physicists' experiments continued to show the effectiveness of using radiation, x-ray and radiotherapy to attack cancer cells, with a parallel increasing aversion by some surgeons to the unnecessary mutilation and debilitating procedures of the radical and super radical mastectomies. There developed in England in the late 1940s a surgical breast cancer discourse that 'less was better', and the medical gaze returned to the former practice of the removal of the tumour only. Surgeons such as Geoffrey Keynes, Robert McWhirter and David Patey urged the abandonment of radical mastectomies in favour of modified mastectomies, simple mastectomies, and lumpectomies combined with radiotherapy. For women with operable tumours, surgeons thus began to perform lumpectomies, or 'tylectomies' on small lesions, and simple mastectomies on larger ones (Keynes, 1952). Slowly up to the 1960s, the Halsted radical mastectomy and the super radical mastectomy as the preferred treatments for breast cancer fell into decline as oncologists continued to develop and refine radiation treatment and anti-cancer drugs.

In the late 1940s, British surgeon and academic David Patey, in particular, was prophetic in his understanding of the future of breast cancer oncology by his investment, like others before him, in the discourse that the disease was not a local entity but systemic in nature. "Until an efficient general agent for the treatment of carcinoma of the breast is developed, a high proportion of cases are doomed to die of the disease whatever combination of local treatment by surgery and irradiation is used, because in such a high proportion of cases the disease has passed outside the field of local attack when the patient first comes in for treatment" (David Patey, 1948, quoted in Ellis, 2001, p. 178).

This search for Patey's 'general agent' was a big shift away from Fabricius Hildinus' 1600s distillation of suckling puppies, wine, goldenrod water for application to ulcerous carcinoma of the breast (Jones, 1960). The long history of the quest to find a cure or to advance the treatment of breast cancer was colourfully described by a physician W. S. Bainbridge at the New York General Memorial Hospital on the eve of World War 1. "Throughout the centuries the sufferers of this disease [cancer] have been the subject of

almost every form of experimentation. The fields and forests, the apothecary shop and temple have been ransacked for some successful means of relief from this intractable malady. Hardly any animal has escaped making its contribution in hide or hair, tooth or toenail, thymus or thyroid, liver or spleen in the vain search of a means of relief” (Bainbridge, quoted in Faguet, 2002, p. 73).

Thus began the active search by science for new chemotherapy drugs, and chemotherapy was added as the third treatment modality for cancer, combined with increasingly more effective surgery and radiation.

In what can be viewed as a Foucauldian rupture from the 2<sup>nd</sup> century theories of Galen, Aetios and Paul, an alternative theory to Halsted was formulated and put forth in rather definitive terms in a 1980 lecture by Dr Bernard Fisher, professor of surgery at the University of Pittsburgh. Fisher argued that breast cancer was a systemic disease, and that variations in effective local regional treatment were unlikely to affect survival substantially (Travis, 2005). Fisher, a surgeon, pathologist and endocrinologist at the London Postgraduate Medical School and University of Pittsburgh, proposed a new logic of metastasis that breast cancer could spread through both the lymphatic and bloodstream because the two vascular systems are so united. He contended that this complexity made the timing of the start of spread difficult, if not impossible to ascertain. The frenetic, almost obsessive insistence on immediately performing surgery or other treatments lost its urgency, and women were thereby given the option of more time to prepare themselves emotionally for what might lie ahead. However, the scientific approach remained the dominant one, and its practices did not to help women address their feelings of anxiety. In November 1970, Fisher wrote, “Right now, nobody really knows what the best treatment for breast cancer is. But no clinical therapy should be determined by emotion or conviction – the determinant must be the scientific method” (Fisher, 1970, p. 121).

Given that cancer was now largely accepted as a double vascular systemic disease, and that it was the immunological system which could save a patient’s life, scientists had to continue to develop effective anti-cancer drugs which would reach every cell in the body. At this point, most of the anti-cancer drugs in use today had already been synthesised, but the development of combination chemotherapy regimens – different drugs to affect cancer cells at different stages of cell division – was producing positive results in reducing the ‘malignant burden’ on the immune system (Travis, 2005).

A further challenge to conventional wisdom occurred when, in 1994, Dr Samuel Hellman of the University of Chicago reviewed the history of theories of breast cancer development ('natural history') from 1894 to the present, and stated the case for what he termed the 'spectrum theory' (Hellman, 1994). This fourth dominant construction of the cause of breast cancer considered the disease to be heterogeneous, combined or a spectrum of disease with increasing tendency for metastasis as a function of tumour size. Hellman used the terms 'local control' to mean lumpectomy or mastectomy, and 'regional control' was to be provided by radiotherapy and chemotherapy. He speculated that persistent local or regional disease may give rise to distant metastases, and therefore the combination of 'loco-regional' therapy was the most effective in preventing recurrence.

Some physicians at about this time began to postulate that the size of the tumour was less significant than its biology, and that early detection and swift treatment might even be irrelevant, because the outcome for most breast cancer patients was predetermined by the biological imperatives of their cancer cells, regardless of the treatment course adopted (Lerner, 2001). This approach focussed attention on the importance of the prior existence of the tumour when making treatment decisions, and turned on its head the prevailing practice of surgeons to not delay and to perform surgery as soon as possible. "The cancer has typically been there for six years if it shows up on a mammography and eight to ten years if you can feel the lump" (Ferraro, 1993, p. 46). Delay in treatment was considered not so dangerous, and gave women time to become better informed and empowered in the treatment decision process.

The therapeutic implications of this new systemic theoretical discourse have been large. Breast cancers are now viewed as systemic diseases. Under this theory any distant metastases of any significance have already occurred at the time that a breast tumour is found by palpation, mammography or ultrasound. Just as Hippocrates had believed two thousand years before, and despite its Foucauldian discontinuities and re-appearances, breast cancer is now constructed in medical discourse as having been a systemic disease from its very beginning, and that modern cures for systemic diseases have to be systemic as well. Competing for dominance is the findings of current research into the genetic makeup of cells and inherited defects in DNA repair genes, such as BRCA1 and BRCA2 (American Cancer Society, 2005) which has confirmed the medical truth that there is a strong hereditary link for females in those families which possess these genes (McPherson et al., 2000; Welsch, 2009). This has contributed to a collective fear

amongst women, and led to the emergence of genetic testing for individualising risk and the option of prophylactic double mastectomy for hereditary breast cancer (Hallowell, 2000; Lemke, 2013; Press et al., 2000). Obviously medicine considers that being female is a risky business. However, again with particular reference to breast cancer, it is the surgical discourse which has dominated, despite the myriad of other sub-disciplines that have appeared, such as medical oncology, radiation oncology and immunotherapy and genetics (McCarthy, 2005; Baum, 1992; Welsch, 2009).

### **The Early 21<sup>st</sup> Century Multi-gaze on Breast Cancer**

*The Breast Cancer Wars* (2001) is the title given by Barron Lerner to his book in which he writes of the hopes, fears and pursuits by the medical profession, but also by many other and varied invested parties representing ‘risky’ women, of a cure for breast cancer in the 21<sup>st</sup> century. The years between 1990 and 2000, saw significant and complex variables which impacted on this endeavour. The voice of women vied vehemently with that of the mostly patriarchal medical specialist. The mid-1990s, however, also saw the emergence of more female breast surgeons and specialists, which has impacted significantly on the role of sex in science and medicine, as has the current favouring of the more conservative lumpectomy surgery followed by radiotherapy and adjuvant prophylactic drugs, and cosmetic breast re-constructive surgery. Oncologists have attributed treatment success to an accumulation of incremental factors such as early detection, improved surgery and chemotherapy, and drugs such as the oestrogen blockers for pre- or post-menopausal women, tamoxifen, letrozole, Arimidex, and Herceptin, which target actual flaws in cancer cells. The prescription of so-called anti-cancer drugs, the implementation of breast screening programmes, breast health promotion (Petersen, 1996b) and the exercise of other disciplinary techniques or biopolitics of a specific population of women, are inextricably related to the formation of breast cancer knowledge (Foucault, 1980; Klawiter, 2008) through the medicalisation of breast cancer as a disease continuum, and of women’s bodies. The transformations of breast cancer discourses over very long periods of old time, and within compressed recent periods, reflect the varying spaces in which the female body and the breast have come to be located (Dean, 1994; Foucault, 1973; Lupton, 1994; Nettleton & Watson, 1998). This is Foucault’s power/knowledge (Foucault, 1980) – the correlation between what is knowable or thinkable about breast cancer, and the techniques of disciplinary power employed by medical and public health regimes and campaigns to regulate the

body (Lupton, 1995) and to control the disease as a problem (Bradby, 2012; Dreyfus & Rabinow, 1982; Foucault, 1991, 1988).

Some of the major issues at the interface between medicine and society now include medical contentions of the correlation between abortion and breast cancer (Brind & Chinchilli, 2002), and that non-breast-feeding mothers, lesbians and career women who postpone having children or bear no children at all are more at risk of developing breast cancer, and that age, genetics, and socio-economics are also risk factors (Anderson, 2002; Dibble & Roberts, 2002). Improved diagnostic technology and treatment regimens have led to hundreds of women deemed by oncology to be ‘cured’, but also many thousands being diagnosed. These statistics have given rise to the construction of the incidence of breast cancer as being like a ‘plague’ (Riley, 2006) or of ‘epidemic’ proportions (Kasper & Ferguson, 2000; Lantz & Booth, 1998), and the word ‘epidemic’ has attracted the attention of women in the crisis- or risk-orientated society of current times (Ewald, 1991; Lupton, 1993, 1999b; Mukherjea, 2010; Paul et al., 1999). Breast cancer has come to the fore-front of the women’s health movement, and feminist and gender issues in medicine and breast cancer treatment have stimulated political movements and funding dilemmas, and the rise of wider supportive networks and groups. From a Foucauldian perspective, issues of bio-power related to breast cancer currently sit within two regimes – the regime of medicalisation and the regime of the bio-politics of screening and anatomo-politics of treatment (Foucault, 1978; Gastaldo, 1997; Klawiter, 2008). It is at the point where these regimes meet that the intersection between medicine and the bio-politics of social movements is most clearly seen.

Whether viewed from a traditional historical or a Foucauldian lens, at the beginning of the first decade of the 21st century it remains a medical truth that while mortality rates have decreased markedly, there is still no cure for breast cancer, or indeed most cancers, despite the many debates on treatment (Kolata, 2006). This is because the disease is now constructed as complex, diverse, individual and intricately and subtly connected to medical, anatomical, genetic, environmental, psychological and socio-cultural variables (Lipmann, 2011). The problematisation of breast cancer has become more complex for medicine over time, rather than less so, and has brought a myriad of psychological and social issues, debates and dilemmas for women and for health professionals (Deacon, 2000; Fosket, 2000). It is difficult to say whether modern women are more aware of breast cancer than their ancient counterparts, or whether they are more fearful of it because of its high profile and multitude of associated factors posted in the modern

media and information technology more so than in any other time in history. The breadth and depth of the breast cancer medical archive is an indication of how the disease has resonated across individuals, groups, epochs and cultural contexts (Turner, 1992). Breast cancer has always been a disease of women, and feared by women, with significant emotional and social ramifications. As a result, social and medical commentators reflect that just about everything about breast cancer has generated controversy and debate. As Italian oncologist Gianni Bonadonna so succinctly put it in a key-note address on improving the doctor-patient relationship, “The problem with breast cancer is not the breast” (quoted in Olson, 2002, p. 206). These socio-cultural surfaces of emergence for constructions of the experience of breast cancer are explored in my next chapter.

## **Summary**

Put simply, as the medical gaze and theories have shifted from the humors, to anatomy, cell theory, and multiple aetiologies, so too has its object of concern. In this chapter I have reviewed the Foucauldian critical modalities of breast cancer as they have appeared in the medical literature, and highlighted how dominant definitions, explanations, diagnostic and treatment methods of the disease have emerged over different medical epochs. The history of breast cancer has been institutionalised within medical faculties and is largely dedicated to a conservative historiography of ideas, physicians, institutions and treatments serving the ideological needs of the normalisation of the body by the medical profession (Canguilhem, 1989; Foucault, 1973).

Consistent with the Foucauldian argument, in this literature review I have explored these normalising techniques as they have been, and continue to be, contested by the scientific and medical groups involved with breast cancer. The review shows that the development of their various concepts, constructions and theories has been an uneven and ambiguous process which has resulted in persistent re-assessment and re-negotiations of norms over a very long period of time. Inter- and intra-professional conflicts show issues of ownership, rationales, politics, paradoxes, and contradictions in the discursive constructions of causes, diagnosis and treatment of breast cancer, with various oncological activities, at both collective and individual levels, attaining differential privileges at different times.

Overall, four main theories of disease - humoral, gross anatomical, micro-cellular and multiple causative factors - have allowed the medical gaze to define breast cancer and its aetiology over a very long period of time. The truths of breast cancer have been, and continue to be unsettled by new discourses and discursive practices which have opened up other ways of constructing the disease, and its various disciplinary power systems. Through the lens of Foucault's notion of rupture or discontinuity in history, this literature review has shown the co-existence, over-lapping and competitiveness of medical theories about breast cancer. Overall though, the medical discourse, and particularly the discursive practices of surgical intervention, has dominated all other discourses in the empirical literature related to breast cancer.

In the next chapter I review the empirical literature, again from a Foucauldian lens, of how socio-cultural discourses have predominantly constructed the experience of breast cancer over its long history up to the present. I identify key examples from the literature of how women patients and health professionals have predominately constructed and reacted socially and psychologically to breast cancer. My purpose in presenting the second literature review, in addition to the current one, is to 'set the scene' for my own identification and analysis of enduring and new dominant breast cancer discourses deployed in by the women and health professional participants in my study in the first decade of the 21<sup>st</sup> century in New Zealand.



## **CHAPTER FIVE: THE GENDER AND FEMINIST DISCOURSES CONCERNING BREAST CANCER: A LITERATURE REVIEW**

### **Introduction**

In the preceding chapter I presented a review of the empirical literature regarding the medical construction of breast cancer from a Foucauldian viewpoint. From a post-structuralist perspective, the discourse which predominantly constructs the event or discursive object of breast cancer is the medical discourse. The basic Foucauldian tenet is that there are multiple truths concerning an object or experience, and that each discourse has its own criteria about what constitutes its truth (Foucault, 1972). While the medical construction is the most dominant, there are other discursive constructions. Secondary discourses by which the female body and breast cancer have been commonly constructed in the post-structural literature are gender and feminist.

Given that being identified, or identifying oneself as a woman, and the associated societal expectations, responsibilities and behaviours of this identification, as articulated by both the women and the professionals, it is important that I clarify at the beginning of this chapter how I have demarcated the meanings of ‘gender’ and ‘sex’, and applied them throughout the rest of the thesis.

While it seems obvious that sex is a biological term and that gender is a sociological description of identities and roles, there is a tendency in modern discourse to confuse the two. This blurring of meaning of sex and gender becomes even more apparent when one considers biology in social settings, or as Fausto-Sterling (2012) puts it, the cultural side of science and the scientific side of culture. The conflation or conjoining of sex and gender as the same thing can mean that there is a risk their differences will be overlooked or lost if each is not used appropriately in context. In order to overcome this risk, I have used ‘gender’ to mean the associated constructions of behaviour, attitudes and social expectations of what are considered femininities and masculinities – in other words, the gender role and the gender role discourse. In doing so, I have attempted to incorporate the contemporary approach to theorising masculinities and femininities as multiple, fluid, locational and historically specific. I have used ‘sex’ to mean the biologies of male and female.

Gender research with a focus on language has been consistently innovative since its inception, drawing on theoretical frameworks and methodological approaches from diverse disciplines. The trend is followed in this chapter by the application of a post-structural discourse analysis perspective, drawing on key Foucauldian concepts to an empirical review of how breast cancer has been discursively constructed in various gendered and feminist ways over time. As an alternative to the medical lens, the chapter also includes a review of how these constructions have contributed to contemporary gendered explanations, imagery and the discursive practices that empower and disempower women and health professionals when related to breast cancer.

The literature showed that there are three major ways in which the female body and breast cancer are constructed when viewed through a Foucauldian-inspired gender and feminist lens – (1) gendered constructions of the woman and the woman's body and the sexualised and functional female breast, (2) feminist discourse constructs breast cancer as a gendered and feminist event, with the female body as the unequal site of power and social control between the sexes, (3) the discovery of symptoms, diagnosis, treatment and recovery from breast cancer compromise women's identity, femininity and self-worth. I have chosen to organise this literature review using these three gendered constructions, albeit that they over-lap and are inter-linked. The purpose is to provide a contextual overview for my own post-structural and Foucauldian discursive analyses of the study participants' accounts within gendered and feminist contexts of the female body and breast cancer.

### **Gender and Feminist Discourses**

Foucault (1980, 1982a) explicated how specific historical and cultural practices constitute distinct forms of self-hood. The last two hundred years have seen what he would have described as a “discursive explosion” (1978, p. 38) with reference to the meaning of sexuality and gender. The second half of the 19<sup>th</sup> century in particular was a period in which the mechanisms of science, law and bureaucracy formalised sexual essentialism, and the idea of a ‘true self’ and a singular identity based on one's ‘innate’ femininity or masculinity took hold in Western society (Diamond & Quinby, 1988). Since the 19<sup>th</sup> century, in Western culture, patriarchal science and sexist discourse have constructed the female and male body as essentially different and always sexed (Walkerdine, 1990; Weedon, 1987). While gender is now considered a philosophical construct, it is not known precisely when and where it was first used to refer to the social and cultural aspects of sexual difference, but it was certainly current in sexology

by the early 1960s (Foucault, 1988; Glover & Kaplan, 2000; Marecek, et al., 2004). In our highly gender-divided and stratified nature of social practices, gender is central to our definitions of human subjectivity (Burman, 1995). Subjectivity and identity are constructed within mainstream social discourse as unitary aspects of the gendered self, upon which individuals strive to impose some degree of coherence and consistency. Gender is a very significant facet of one's social identity – a pervasive social influence on everything one does and says, with social interactions typically viewed through 'gendered' spectacles much of the time (Eckert & McConnell-Ginet, 2003). As Holmes (2006) has argued, "our discourse is drenched in gender" (p.26).

### **Gender Identities**

Current approaches to the study of language and gender focus on the dynamic ways in which people draw on discursive resources to construct their social identities, especially their gender identities in different social contexts (Holmes & Marra, 2010; O'Brien, 2009) and in specific communities of practice (Eckert & McConnell-Ginet, 2003). Gender is a critical component of social meaning, an aspect of social identity conveyed indirectly through the choice of particular linguistic and discursive features, which may be multi-functional (Cameron, 2009; Cameron & Kulick, 2003; Holmes, 1997). This understanding is in contrast to seeing gender as a property of a person or as a set of adjectives associated with a person. In this review, and throughout the study, I have chosen to use the definition 'gender discourse' because of its construction of male and female as discrete discursive objects. The dynamic process of the gendering of breast cancer is the product of distinctly male and female subjectivities and practices, and the significance of the gendered associations these hold (Cameron & Kulick, 2003). As the literature review in Chapter Four showed, the medical discourse related to breast cancer is exceedingly dominant, but the gendered constructions by which the woman's body containing breast cancer is viewed as other than a purely medical event, are also well represented in empirical studies (Ussher, 2007; Watkins & Whaley, 2000). "Gender is one of the primary effects of the discursive construction of the human body" (Balsamo, 1996, p. 22). Woman has been measured and judged against the norm of man. Biological deviation from the male standard marks women as biologically and therefore 'naturally' inferior, "victims of a pathological physiology" (Balsamo, 1996, p. 42). Women are commonly described as the 'other half' (Bailey, 1993), further polarising the categories of the orderly male and the unruly body and nature of woman.

## **Feminist Literature**

Feminist research identifies how women are subjugated primarily through their bodies, and how gender ideologies and sexist reasoning stem from perceived biological differences between the sexes. These differences are supported by dualistic paradigms that have characterised Western thought from the philosophers of ancient Greece to the Enlightenment and beyond (King, 2004). Their studies explore the interaction between sex, power, gender and knowledge, and draw on analyses which critique structures of oppression including sexism and hierarchies where domination is seen as masculinist power. As Diamond and Quinby (1988) stated, whether it is to produce a particular bodily configuration or to divide knowledge into academic disciplines, power is always gendered. “It [gender] is a pervasive and powerful method of social control that both produces and restricts one’s mode of being”, (King, 2004, p. 36).

Feminist literature, with a focus on breast cancer, has explored women’s bodies, women’s health, and critiqued patriarchal medical science and research and associated frameworks of power, with a commitment to improving the situation of women positioned within the medical encounter (Bartky, 1988; Butler, 1999; Turner, 1987). Such research has focussed particularly on the power dynamics which are structured into the physician-patient relationship, and which are shown to be deepened by the sexist inequalities and disparities between male surgeons and female patients. Medical and scientific discourses have confirmed the pathology of female biology and legitimated women’s subjugation in the ways that the female body has been subjected to the scrutinising gaze of the human sciences far more than the male. Because of its inherent pathology, numerous fields of expertise about womanhood have arisen – ‘inventing women’ (Kirkup & Keller, 1992). Foucault’s work has been very influential amongst feminist scholars, with reference to power and its effects on the body, and the disciplining of the female body (King, 2004). Although his work is gender-neutral, feminist writers have exposed this omission, and explored the polarisation of the two sexes in their readings of the female body, especially the female breasts, as a particular target of disciplinary power. Key feminist post-structural discourse analysis writers (Baxter, 2008; Bordo, 1990, 1993; Butler, 1990), and those with a focus on breast cancer, have explored the gendered nature of definitions of illness and treatment, and the ways in which breast cancer in particular involves male control over women’s bodies, lives and identities (Baxter, 2003, 2006, 2008; Kasper, 1994).

## **Foucault and Gender**

Foucault has been criticised for his almost total neglect of gender, women's issues, feminism, and sexual specificity, and has been accused of being 'gender-blind' and androcentric (Diamond & Quinby, 1988; Jones & Porter, 1994; King, 2004; McLaren, 2002; Ramazanoglu, 1993). Even in his discussion of bodies, he did not make distinctions between male and female bodies or between feminine and masculine disciplinary practices, and in his discussion of the formation of the ethical subject, he focused on the male subject (Bartky, 1988; McLaren, 2002). Nevertheless, a review of the literature shows that Foucault's concepts of discourse, subjectivity and power/knowledge have been applied in many research areas which have explored the body and gender.

While a Foucauldian approach generally objectifies the body and disease, there are many gendered meanings of the woman, the woman's body, and breast cancer. For the purposes of this review I searched for studies which explored post-structural and Foucauldian approaches to how the gender and feminist discourses construct the object of the woman and the woman's body before and after breast cancer. This revealed the conditions of existence or factors which allow the gender and feminist discourses to come into being in the first place (Foucault, 1972; McHoul & Grace, 1995). The literature also shows the surfaces of emergence (Foucault, 1972) or where things about breast cancer are played out, such as the clinic or medical treatments, the home and family (Foucault, 1972, 1973), and the subject/speaking positions and subjectivities of the speakers taken up within such settings. With these points of reference, my literature search focussed on the Foucauldian notions of the gendered body, the gendered subject, gendered normative categories, and notions of gendered (particularly feminist) power and ethics.

The idea that gender difference is socially constructed is a view present in many philosophical theories about sex and gender (O'Brien, 2009), and there are many theorists who have used Foucauldian approaches to theorise its meanings. For example, Butler (1990) contended that gender is something that is done, and that subject positions are the basis on which gender identities are formed, and define what it means to be a man or a woman in a given society. As described in Chapter Two, certain discourses are more dominant than others, and these hegemonic discourses determine how the ideal man or woman is supposed to be, and subordinates other ways of enacting gender. According to this view, society and culture create gender roles, and these roles are

generally considered the ideal or appropriate behaviour for a person of that specific gender. Discourse analysis has the capacity to provide insight into how gender is produced in specific interactions, particularly between doctor and patient (Goodyear-Smith & Buetow, 2001; Reed & Saukko, 2010).

### **The Gendered and Feminist Critical Modalities of the Woman's Body and the Sexualised Breast**

The gendered construction of the female breast as erotic is deeply rooted in the evolutionary past (Wilkinson & Kitzinger, 1995). Only in human beings do female breasts appear during puberty instead of with the first pregnancy. Breast development constitutes an external, visual sign of puberty, and its role in sexual arousal and reproduction is deeply embedded in the psyche of human beings (Anderson, 1983), and is a type of psychological discourse (Potter, 2012). Foucault's work articulated a notion of subjectivity that is embodied, and constituted historically through social relations, in this case, the social relations of sexual allure and the sexual act (Crossley, 1994; Eckermann, 1997; Foucault, 1991). The female body has become both the reproductive and the sexual body – the object of interest and regulation through pre-ordained marital and domestic roles (Lind, 2008; Ryan & Jethá, 2010). The history of the 18<sup>th</sup> and 19<sup>th</sup> centuries shows how middle class women regarded their bodies as commodities to be preened and maintained in order to entice men into matrimony, and thus have the material means to live (Davis, 1991). Women's attention to their bodies therefore, took the form of producing them as objects of others' appraisal, a construction noted in feminist work up to the present day (Lennon, 2010).

#### **"The Body as a Text of Femininity" (Bordo, 1989, p. 13)**

Patriarchal discourses of femaleness and femininity have constructed the woman with breasts as an object to be known sexually, her breasts to be looked at and fondled, and the mother, with breasts, as carer and nurturer. The link between sexuality and reproduction are deeply biologically and socially intertwined (Broad et al., 2006). Femininity and the role of mothering have long been fashioned in images, models and toy dolls, most conspicuously in recent times by the Barbie doll, appearing first in 1959, though the doll has unattainable body proportions (Kasper & Ferguson, 2000; Lind, 2008). Such images and 'breast slang' continue to perpetuate the representational production of ideal female breasts in the service of 'normative femininity' (Naugler, 2009; Walkerdine, 1990).

The female breast has been portrayed as a symbol of fertility and erotic arousal in art history for thousands of years (Braithwaite & Shugg, 1983; McDonald, 2001; Olson, 2002; Webb, 1977), but most particularly of eroticism and beauty by Western society from the second half of the 20<sup>th</sup> century (Suleiman, 1986) and into the beginning of the 21<sup>st</sup> century (McDonald, 2001). The sexual revolution (just like the second Industrial Revolution), and modern feminism, dramatically and enduringly altered the cultural and political landscape, changing forever attitudes about power, eroticism, and physical beauty. These changes of thinking and discursive practices about the female body and power show the coming together of Foucauldian theory and feminist history.

### **The Breast as a Site of Feminist Power**

Much feminist research has focussed on the female breasts as a particular target of disciplinary power, and particularly in the ways in which some fashion and beauty practices manipulate, train and mark the female body (Davis, 1991; Bordo, 1993). Fashion styles have exposed more flesh to public view, and as a result women worry about individual body parts (Wilson, 1985). Soft-core pornography and topless clubs, plastic surgery and silicone-enhanced breasts, push-up brassieres and ‘falsies’ were some of the free expressions of the cult of the breast of the 1970s and 1980s, but the feminist or women’s movement ran counter to this obsession with breasts, and encouraged women to break free by disposing of bras, girdles, high-heeled shoes, curlers, and other “instruments of torture to women” in “freedom trash cans” (cited in Olson, 2002, p. 118). Some feminists have researched woman as an “ornamented surface” (King, 2004, p. 36), giving rise to feelings of inadequacy, and requiring discipline. Such thinking cements woman’s status by some as merely a body, and confirms her role as primarily decorative. Western culture has a tendency to emphasise women’s bodily appearance over other qualities as determinants of social acceptability and self-worth.

In general terms, there has developed a cultural expectation that to be considered beautiful and sexually attractive, women need to have two large breasts, and many studies have reproduced the objectifications and stereotyping of our sexist culture (Langellier & Sullivan, 1998). The medicalisation and the gendering of women’s breasts, in combination, demonstrate that medicine and society have not only sexually objectified women’s breasts but commonly viewed them as diseased or deformed. Breasts that do not conform to society’s idealised image should be altered – shaped, re-shaped, enlarged, implanted or reduced, thereby being made to fit a socially defined size

and shape. For most women, the messages they have received throughout their lives are that women are defined by, and primarily valued, for their appearance, and that a woman's appearance is largely defined by her breasts (Kasper & Ferguson, 2000; Young, 2005). "In the total scheme of objectification of women, breasts are the primary things" (Young, 2005, p. 190). Breasts have assumed an aura of cultural power by society placing on them such large value, breasts and physical beauty having become almost synonymous. "Woman is entrenched in her physicality" (King, 2004, p. 31) – "a thing sunk deeply in its own immanence" (de Beauvoir, 1988, p. 189).

### **The Gendered and Feminist Critical Modalities of the Female Body as a Site of Power**

The history of sex, gender and feminism shows that modern patriarchal cultural and scientific domination began with the age of Enlightenment, which viewed women (and nature) as passive, worthless and dispensable, and therefore to be controlled, exploited and disposed of (as seen in witch burnings) (Morales, 1998; Rose, 1994; Yalom, 1997). In most cultures, indigenous knowledge in women's (witches') hands was integral to the maintenance of health – caring, midwifery, herbalism and other modalities included the interplay of body, mind, spirit and earth (Merchant, 1990). In modern Western society, for the most part, women have lost the knowledge of their own bodies, as 'professionals' dictate medicine and health and other procedures to be followed. 'Women's ways' have been negated by modern medicine, and increasing dependence on complex technologies has accelerated the trend towards specialisation and has enforced a tendency to look at particular parts of the body, neglecting to deal with the whole person (Armstrong, 1983; Lupton, 1997; Rose, 1994).

The feminist project of exploring the micro-politics of personal life, and exposing the mechanics of patriarchal power at the most intimate levels of women's experience, is especially relevant to the breast cancer story (Kasper, 1994; Kasper & Ferguson, 2000; Sawicki, 1998). For example, feminist research has explored the way in which breasts, while signifying femininity, are not the preserve of the woman who has them, but are 'claimed' by lovers, children, and in the case of breast cancer, the medical profession (Bartky, 1988, 1990; Holmes, 2006; Lupton, 1994a). The doctor dominates, exercising a strong paternalism over the subordinate female patient (Goodyear-Smith & Buetow, 2001; Stewart & Roter, 1989). Bartky (1988) argued that modern forms of femininity render women's bodies docile in ways quite distinct from contemporary Western society's disciplinary practices for men.



Code (1995), in her essays on gendered locations, developed the concept of rhetorical discursive spaces as social locations whose tacit rules structure and limit the kinds of utterances that can be voiced with a reasonable expectation of being heard, understood and taken seriously. Medical discourse assigns the privilege of knowing about women's health and illness to the voice of medicine (Armstrong, 1997; Bunton & Petersen, 1997; Lupton, 1997; Mishler, 1984), and its power-induced practices disqualify certain speakers, especially those of female patients. But gender is also often the ruling force in rhetorical discursive spaces of breast cancer (Malterud, 2000).

### **Feminism, Foucault and the Female Body**

Much feminist literature has been critical of Foucault (Bartky, 1988; Diamond & Quinby, 1988; McLaren, 2002), and has identified gaps in his genealogies that purport to detail disciplinary power's operations in the deployment of sexuality (Foucault, 1978, 1988), while overlooking women's writings on issues like pregnancy, abortion, birth control, anorexia, bulimia, cosmetic surgery, and treatments for breast and uterine cancer (Bordo, 1993; McLaren, 2002). Both first- and second-wave feminists have documented far-ranging, deeply structured forms of masculinist domination which have identified women's bodies as the locus of masculinist power (Hatty, 2000), such as the medicalising of women's bodies which made pregnancy into an illness and undermined women-centred healing institutions, the physical and sexual abuse of women, and the mutilation of women's bodies for the sake of 'beauty'. The language and politics of personal relations and gendered power relations at the most intimate levels, feminists claim, are never gender-free (Diamond & Quinby, 1988).

As described above, at face value it appears that women were rarely represented in Foucault's work (Diamond & Quinby, 1988; Jones & Porter, 1994; King, 2004; McLaren, 2002; Ramazanoglu, 1993); however, some key medically-minded feminist writers (de Lauretis, 1989; Diamond & Quinby, 1988; Sawicki, 1991, 1998) have suggested that a number of convergences between the Foucauldian and the feminist historical projects offers an insight into the crucial role of discourse in its capacity to produce and sustain a different sort of power within the doctor-patient relationship. For example, Foucault and some feminists have both criticised the ways in which Western humanism has privileged the experience of the Western masculine medical elite (Goodyear-Smith & Buetow, 2001; Leopold, 2000; Little et al., 1999). Foucault and feminists also identify the body as a site of power, and both point to the local operations of power within the more intimate doctor-patient consultation and to the wider supreme

power of state medical systems. With the influence of the sexual revolution and the feminist movement, an ironic conjunction of medical disciplines, scientific evidence, sex and gender politics and sexism generated a new intellectual and medical discourse in which male breast surgeons and female patients faced each other (Reed & Saukko, 2010).

The feminist movement brought into the open issues of inequality in the world of medicine (Foucault, 1973; Holmes & Purdy, 1992), and sought to redefine the subordinate relationship between female patients and their doctors. The male physician-female patient connection was considered to be among the most paternalistic of all relationships (Stewart & Roter, 1989). This was not unexpected as the vast majority of doctors were male and 99 per cent of breast cancer patients were female. Records of doctors' thoughts revealed that they expected their patients to accept their advice about treatment unquestioningly (Mukherjee, 2010). However, competing feminist discourses began to appear in the early 1970s, especially in the best-selling book *Our Bodies, Ourselves* about women's health and sexuality, compiled by the Boston Women's Health Collective (1970). The feminist contributors urged women to take control of their bodies and thereby take control of the male-dominated health-care system. The book contained this statement,

...doctors are not gods, but human beings with serious problems, both as people and as professionals. But so, of course, are we all. The uncomfortable difference is that the system has taught the doctor never to reveal his problems and weaknesses to us, to present himself as perfect and all wise, whereas the essence of patienthood is that we must reveal all of our doubts and vulnerabilities to him...The myth still persists that we meet one another as parent and child, and that you as patient must both obey and pay money for the privilege (Boston Women's Collective, 1970, p. 102).

The book is now in its 12th edition, and published in over twenty languages and Braille. The current edition is called 'a new edition for a new era', with the amended title *Our Bodies, Ourselves for the New Century* (Boston Women's Collective, 2011). *The New York Times* has called the book a 'feminist classic', and many women refer to it as their 'bible'. This was the beginning of women's collegial call of encouragement to other women to act as independent consumers of professional services, warning them against any procedures that they did not understand or want (Moloney & Paul, 1991). Over time,

medicine has been forced to develop protocols which have shifted the governmentality of the doctor-patient relationship, but the female body remains a contested site of power (Birke, 2000; Reed & Saukko, 2010; Twigg, 2002).

### **The Female Body as a Patriarchal Target of Power**

Foucault's identification of the body as the principal target of power has been used by feminists to analyse contemporary forms of social control over women's bodies and minds. Birth and maternity are areas where patriarchy is acute and the links between sexuality, and reproduction, childcare are biologically and socially intertwined (Broad et al, 2006). Feminist literature is inundated with studies which have explored scientific and sexist biases against female biology and functions – puberty and breasts, menstruation, hormones and hormonal cycles, pregnancy, birth, and diseases of women and women's health. The female body is culturally constructed as “embarrassing” (Lovering, 1995, p. 22), in terms of the social awkwardness ensuing from some of its natural functions – menstruation, pregnancy, birth, breast feeding – and potentially dangerous, should any of these gendered tasks malfunction (Hatty, 2000).

Common in the literature is the portrayal of breast cancer as a female disease emerging out of a female body which is implied to be innately diseased, unstable and problematic (Foucault, 1978; Kasper & Ferguson, 2000; King, 2004; Schulzke, 2011). This image of the female body has become an indelible mark of representations of women and it fits with the traditional image of women being victims of uncontrollable bodies. This research has shown the enduring tendency in medical and gender discourse for doctors to construct female patients' problems as 'typical' feminine neuroses and complaints (Merchant, 1990; Turner, 1987), and their behaviour 'deviant' (Riessman, 1992; Schur, 1984). The concept of a pathological, wandering womb, “blocking passages, obstructing breathing, and causing disease” (Plato, ca 429-347 BCE, cited in Tuana, 1994) for example, was historically viewed as the source of the term *hysteria* stemming from the Greek cognate of uterus, ὕστέρα (*hystera*) in 'passionate' women. The 19<sup>th</sup> century woman continued to be diagnosed with the 'female malady' - frigid, hysterical or neurasthenic, with mental disorders put down to 'disturbances' in the womb (Gilman et al, 1993; Smith-Rosenberg, 1972, 1985; Ussher, 2011). Foucault, in his genealogies (1978, 1988) succinctly referred to the role of discourse as a form of social control through such processes as the gendering of illness (Reagan, 1997). This is especially seen in his description of “the hysterisation of women's bodies” (Foucault, 1978, p.104). “...there was scarcely a malady or physical disturbance to which the nineteenth

century did not impute at least some degree of sexual aetiology...” (Foucault, 1978, p.65). Such patriarchal notions of the hysterical woman, the sexually repressed female, the female who bottles up fear and anger, women’s supposedly emotional, irrational and unstable nature were/are all gendered discursive practices which laid/lay the blame for the development of her breast cancer on the women’s personality (Schur, 1984; Ussher, 2011).

### **Breast Cancer as Punishment**

Most societies deal with illness and disease by ascribing meaning to their aetiology, with bodily processes constructed as innate and gender specific. A dominant Christian discourse of a disease such as cancer was that it was conceived as a punishment appropriate to the character of the individual (Turner, 1996). A classic example of this from the traditional breast cancer archive is that of Queen Anne of Austria in the 17<sup>th</sup> century. “Having seen cancer in nuns who died all rotted with them, she had always had a horror of this disease which she found so frightful even to imagine” (Kleinman, 1977, p. 360; Olson, 2002, p.18). In addition to her fear of the disease, Anne also believed that she was paying penance for her vanity (Kleinman, 1985). “God wishes to punish me for having loved myself too well and having cared too much about the beauty of my body” (Kleinman quoted in Olson, 2002, p.25). In his examination of a medical sociology of 19<sup>th</sup> century women, Turner (1995) also found disease to be a means of penance through which a person can be “re-incorporated back into society through a system of retribution and forgiveness” (p.85). Such discourses of personal responsibility for risk and causation thus represent ways in which women are believed culpable or blame themselves for their breast cancer (Blaxter, 1983; Sontag, 1978). In combination, medical, scientific and gendered discourses have embedded the pathology of female biology, and legitimated women’s subjugation through an increasing dispositive on women’s lives which has seen more and more female ‘conditions’ identified in ways that connote deviation from some ideal biological standard (Riessman, 1992).

### **The Gendered ‘Assemblage’ of Women with Breast Cancer**

By the nature of the diagnosed disease, a person with a genital or a reproductive cancer is constructed by medical, academic, and popular discourse to be either a female or a male patient. A review of the breast cancer literature also suggests however, that these gendered female patients are constructed in the form of emphasised femininity. Breast cancer is most commonly constructed by the interplay of the medical and gender

discourses as a disease, *proportionally of women*, not males (Anderson, 2002). As such, breast cancer is a profoundly gendered disease category. Currently, one woman in eight in New Zealand will develop breast cancer at some stage in their lives (New Zealand Ministry of Health, 2014a). Men also get breast cancer, but the statistic is much less gender-bound, with it being less than 1% of all cancers in men, and less than 1% of all breast cancers (Anderson, 2002). Such statistics represent breast cancer as a typically female condition. Every woman is at risk of developing breast cancer (Gifford, 1986; Harding, 1997; McPherson et al., 2000), and the disease knows no boundaries of age, race, ethnicity or social class across all women and all histories of time (Douglas & Wildavsky, 1982; Kasper & Ferguson, 2000; Mukherjee, 2010; Olson, 2002).

The gender discourse allows the female body to be seen as a “medium of culture” (Bordo, 1989, p. 13), and, as Foucault argued, a direct locus of social control, as well as a material, biological body. In broad terms, the most basic gendered constructions related to breast cancer are the identity of women with breast cancer as female. Through the gender lens, breast cancer has been largely constructed as a personal problem for the individual woman (Reagan, 1997), who once diagnosed, is then categorised into not only medical, but also metaphorical, political, economic, environmental, and normalising strategies and statistics through ‘assemblage’(s) (Deleuze, 1992; Foucault, 1977a, 1991). One such assemblage is the traditional historical and enduring medical and social construction of the childless woman.

The Deleuzian and Foucauldian concept of the *dispositif*, assemblage or knowledge structure which enhances and maintains the exercise of power within the gendered social body of the woman, is commonly found in the socio-medical literature whereby breast cancer is constructed as a disease peculiar to nuns, or women who have not borne children (Anderson, 2002). Breast cancer occupied a unique place in 17<sup>th</sup> century discourses of convent culture. It was known as ‘nuns’ disease’ because of its high incidence among convent women (Fraumeni et al., 1969; Olson, 2002). Such affliction was said by the physicians of the time, to be caused by celibacy and “lack of sexual intercourse which can lead to disturbances in the uterus from which cancerous tumours are generated in the woman’s breast” (Mustacchi 1961, p. 640). Three hundred years later, the conundrum still intrigues modern epidemiologists. The accepted medical thinking is that women are more susceptible to breast cancer, not because they are sexually inactive, but because they are childless. Modern-day biomedical statistics also seem to lean towards accepting that women who have never given birth have a greater

chance of developing breast cancer than women who have had children. Having children earlier rather than later in their reproductive lives is deemed a preventative factor, and breast-feeding lowers the risk of pre-menopausal breast cancer (McPherson, et al., 2000; Russo et al., 2005). Lesbians have been particularly anecdotally implicated, however there is little hard medical evidence to support this, other than many lesbians diagnosed with breast cancer have not borne children, just like heterosexual childless women (Dibble & Roberts, 2002).

From a Foucauldian governmental approach, beyond women who are childless, research also shows that women with breast cancer as a whole are generally viewed as a single group with a single disease of ‘epidemic proportions’ (Kasper & Ferguson, 2000; Lantz & Booth, 1998) – individuals of the same gender grouped together by medical theory and practice (Armstrong, 1995, 1997). Reviews of breast cancer in the gender literature show that up until the early 1970s there was little available information beyond that of health care practitioners and resource literature. These quantitative studies focussed primarily on the technical aspects of the disease (Kasper & Ferguson, 2000), and lumped women with breast cancer together as a homogeneous group. After 1970, there was a burgeoning of research, mostly quantitative questionnaires and surveys that measured women’s moods, attitudes, and coping behaviours. This type of research prevails today, but has limitations because it continues to present women in an already defined framework of meaning which restrains the capturing of the real depth and complexity of the personally gendered female/woman perspective.

While their lives, as well as the reasons or cause of their cancer, perhaps unknown, may be entirely dissimilar, medical and gender discourses objectify a diverse group of women with breast cancer into a stereotypical and homogenous group – what Malterud (2000) called “the gender trap” (p. 605), and such women as “prisoners of gender” (King, 2004, p. 29). Women with breast cancer are thus constructed as a marginalised group, labelled and positioned outside the mainstream lives of ordinary healthy men and women. Foucault (1977a, 1978, 1984) pointed to ways in which such rationalising discourse suppresses the discourses of marginalised groups, and creates sites of resistance. One such site of resistance dominant in the cancer literature emerges from the discourse of mythology, especially when constructing the woman with breast cancer (McKay & Bonner, 1999).

### **The Gendered and Feminist Subjectivities of the Heroine**

Deeper analyses of the cancer discourse have shown that it is a transformative discourse (Burrows, 2010). A woman starts out whole and pure, without cancer, and goes through a journey, as Burrows and others call it, with 'her' cancer. In that journey, she is commonly constructed as the gendered discursive object of warrior, heroine and survivor, who, in her adoption of the survivor narrative, will likely be blamed if she succumbs or dies (Burrows, 2010). In the transformative hero narrative, a woman has also been shown to be transformed into an unfortunate and submissive creature upon whom breast cancer has fallen and against which she must fight to regain her life, femininity and female roles. The same cancer narrative reveals the asymmetry between men and women in that a man with (prostate) cancer is transformed into a flexible and powerful fighter with opportunities to locate his manhood elsewhere on his body and to learn other ways to express his masculinity (Burrows, 2010; Campbell, 2008). With the gaze of medicine, public health, society, and the individual woman on her endangered breast, an ageless discourse of passion, sacrifice and endurance has continued

### **Martyrdom to the Breast**

The discourse of martyrdom, related to the breast, arose in 17<sup>th</sup> century Europe. The convent walls of Austria and Italy were adorned with portraits of such martyrs as St. Agatha of the 3<sup>rd</sup> century (Farmer, 2011; Olson, 2002), who spurned the advances of a Roman consul. After strapping her to the rack and burning her at the stake, he cut off her breasts as the ultimate indignity. Saint Agatha is often depicted on icons carrying her excised breasts on a platter. She is the patron saint of breast cancer patients and martyrs. St. Lucy of the 4<sup>th</sup> century (Farmer, 2011; Olson, 2002), also refused to surrender her dedicated virginity and cut off her own breasts rather than submit to the sexual depredations of her tormentors. The portraits gave hope to women afflicted with breast cancer, and particularly to the larger numbers of nuns suffering from 'nuns' disease' (Fraumeni et al., 1969; Mustacchi, 1961), as described earlier.

The subject position and subjectivity of martyrdom are seen in the large number of women who, through their published pathographies (personal narratives concerned with diagnosis and treatment), are held up as shining examples of women's courage and resiliency (McKay & Bonner, 1999). All of the experiences of the women cited in such publications exemplify the paradoxical nature of breast cancer, and of women's need to overcome its effects physically and emotionally. The expansion of the pathographical

genre or discourse, and the feminist discourse, may be seen as part of recent contestations over the right of patients, especially women, to be publicly heard within the biomedical discourse. In quite complex ways it echoes discursive shifts away from reliance on medical institutions and towards women's personal responsibility for getting one's health back and maintaining well-being (McKay & Bonner, 1999; Roy, 2008; Shaver & Drown, 1986).

### **The Military Metaphor of Women with Breast Cancer**

Fear of cancer is deep-seated (Glassner, 2004a, 2004b; Lerner, 2001), and public use of the word 'cancer' was relatively rare in the first half of the 20th century (Cantor, 1992; Olson, 2002). The foundation of the American Cancer Society (ACS) in 1913 however, was one of the first attempts to alter the public's fatalistic attitudes towards cancer. Strenuous efforts were undertaken to counter ignorance, fatalism and fears through the use of militaristic slogans such as 'Fight cancer with knowledge', and the 'crusade' for early detection, a medical discursive practice which continues today. The American Cancer Society employs a military logo and metaphors linking the 'war on cancer' to American military victories, and uses the rhetoric of fear, mirroring military tactics (American Cancer Society, 2014). Such military rhetoric serves to energise public opinion against cancer, maximise public donations, and provide inspiration and optimism to cancer patients and their families.

Women, and their risky breasts, became a particular target for attention, and a new form of bio-power in the form of a public health focus on breast cancer developed (Mukherjea, 2010). Women were given many types of messages about the risk and dangers of breast cancer, and in response were drawn in to establish their own gendered organisations such as the Women's Field Army Against Cancer (WFA) which promoted 'trench warfare with a vengeance against a ruthless killer', and the more recent Women Against Cancer (WAC) groups. Both included in their literature the insignia of the 'Sword of Hope', a sword with a hilt formed from twin serpents (Lerner, 2001), which remains the emblem of the medical profession. The symbolism continues, with the motto of most cancer charities across the world encompassing the aim of 'combatting' cancer, and the gender-specific coloured pink ribbon worn on lapels for awareness about breast cancer and fund-raising.

The new public health movement was led by surgeons in battle mode, and the dominant discourse in which they invested, "only in the scalpel could women find relief",



strengthened their position of power over the patient. Pamphlets with such wording as “How a wise woman won the battle against cancer”, “She had faith in her physician. He had confidence in his power.” (Patterson, 1987, p.74; my italics), extolled the woman’s qualities of wisdom, faith and possessing a fighting spirit, as opposed to being unwise and lacking faith in the confident and powerful male surgeon. Paradoxically, however, casting cancer as an evil enemy in an effort to energise and motivate has also helped perpetuate the image of cancer as a menace to be greatly feared (Glassner, 2004a, 2004b; Lerner, 2001). While many cancer patients, both male and female, are commonly described as ‘fighting a battle’, breast cancer in particular continues to be constructed in popular, medical and gender discourses as an enemy to be faced and a battle to be won (Faguet, 2005; Goodfield, 1975). This prevailing military metaphor is considered by some writers as a discourse in itself (Reisfield & Wilson, 2004). War metaphors permeate the disease rhetoric and create the sense that women’s bodies are battlefields (Lerner, 2001).

Images of rampant cancer cells had paralleled images of the Industrial Revolution for some commentators at the time (Reisfield & Wilson, 2004). The language associated with cancer evoked social and economic upheaval and uncertainty, and was rich in metaphors, many of which remain dominant in the ways in which cancer is commonly talked about today (Penson, et al., 2004). Metaphorical cancer signifies uncontrolled and incoherent attack, a type of terrorism on and of the body (Schulzke, (2011). For example, using an analogy of possibly the greatest event of terrorism in recent history, women’s tennis champion Martina Navratilova, on being diagnosed at 53 with ductal carcinoma in situ, stated “Getting cancer was like my personal 9/11” (Daily Mirror, 2010). Consumer and pharmaceutical groups have also appropriated these martial and heroic constructions to stimulate the funding of projects in the ‘battle’ against breast cancer (Kendall & Wickham, 1999). The imagery of battle seems to be a commonly shared discourse of medicine and women’s retaliation against breast cancer, in their attempts to restore order and function, and the military metaphor of counter-attack is perhaps the most dominant in the breast cancer discourse (Lerner, 2001). Women being treated for breast cancer are commonly portrayed as triumphant and brave fighters, exhibiting a hostile fighting attitude rather than the stereotypical passive feminine role (Lupton, 1994a). Yet, while gendered, they are still medical subjects - living examples of the victory of medical intervention. Women who die of the disease are frequently described as having ‘lost the battle’ (Lerner, 2001). Analysing the metaphors which

shape our language and construct our experiences helps in the understanding of the impact they can have. As the preceding sections of this review have shown, breast cancer defies understanding, and has produced a large lexicon of metaphors and clichés (Hadju, 2011), which can operate to disarm women and make them fearful and resigned, demoralised or punished, and more than anything else, always at risk.

### **The Female Breast as a Site of Risk – Women’s Responsibility**

Foucault (1973, 1977a) explored the notion of the disciplining by illness in the name of health. Society has come to celebrate normality and to criticise all those who threaten it through risky behaviour (Lupton, 1993; Petersen & Lupton, 1996), and experts have taken on the role of ‘masters of lifestyle’ (Rose, 1994), particularly of women’s lifestyles (Nettleton & Watson, 1998). Risk has been forecast to become one of the defining cultural characteristics of Western society in the new millennium (Lupton, 1999a, 1999b), especially in the ways that health is described, organised and practised, both personally and professionally. Aligned to the high profile of breast cancer is the increased perception of the risk of its symptoms being discovered and diagnosed (Press et al., 2000; Robertson, 2000; Tritter & Calnan, 2002).

The discourse of risk, when applied to breast cancer, can be seen to draw on traditional gendered discourses but simultaneously on notions of the ‘responsible woman’ central to the new public health discourse (Petersen & Lupton, 1996). Risk management strategies undertaken by women themselves, are constructed as the enterprising actions expected of reasonable, morally responsible, ‘at-risk’ women, in order to maintain their own health and to continue in their gendered roles of caring for their families - and often blamed and seen as irresponsible in disparaging and patronising ways (Lupton, 1993, 1994a) if they do not. Health is strongly associated with morality in modern Western culture, and improper lifestyles or practices are frequently cited as the root of illness (Turner, 1996). The woman who does not seek regular mammography screening ‘has only herself to blame’ is common talk (Houldin et al., 1996; Shaver & Drown, 1986), with a blameful logic of individual responsibility built into it.

### **The Breast Examination as a Gendered Technology of Power**

From the mid-1950s up to the early 2000s, breast self-examination (BSE) had nearly uncontested support in mass media accounts as a proactive and responsible practice of self-surveillance. However, more recently, a number of breast cancer activists have spoken out against the practice, constructing it as oppressive and fostering victim-

blaming (Kline, 2000). The discourse of popular media on the issue of BSE, blames women for not doing their part to reduce high breast cancer mortality statistics, and chastises them for failing to engage in the activity. From either perspective, women are subjected to an agency-robbing discourse. Some people, for cultural, religious or personal reasons, believe masturbation and autoeroticism to be wrong, and see the examining of one's breasts as closely aligned to these taboo practices (Estes, 2013), or at least as an unnatural activity. Many women choose to defer to the 'safe' and 'professional' practice of health professionals, or even safer digital technology, but also feel empowered by participating in the discursive practice of talking about it with their GPs and/or other women. Reforming the BSE rhetoric thus facilitates a more therapeutic and individually empowering self-help activity (Kline, 2000).

Discourses on breast cancer serve to maintain a constant level of anxiety about its high prevalence and death rate. Psychological or emotional stressors have been found to be associated with women's embarrassment, fear, reluctance to self-examine or have their GP examine, undergo mammography, or face treatment (Altheide, 2002; Lerner, 2001; Lupton, 1994a).

The process of surveillance in testing such as mammograms serves the panoptic function of making women dependent upon the insight of technology to reveal the mysteries of their [breasts], redefining notions of health and illness by constantly placing emphasis upon the potential of hidden disease lurking within an apparently healthy body (Lupton, 1994a, p. 84).

Discursive practices relating to breast cancer continue to privilege the ideology of the "technical imperative" for women (Lupton, 1994a, p. 84). In the context of breast cancer, the constant emphasis upon the risks to which women are exposed has the effect of creating a "constant threat of unquenchable anxiety" (Baines 1990, p. 20) in women who have been labelled 'at risk', and of rendering symptomless women potential victims (Lupton, 1994a). "It's just part of being a woman", (Bush, 2000, p. 429).

Taking care of herself through breast self-examination or technology, has been found in the medical, public health, gender and feminist literature to be a large part of a woman's obligation to her family and home. This gendered message is embedded in the notion that maintaining the domestic sphere is fundamentally a woman's responsibility (Roy, 2008), and shows Foucault's (1984) notion of a disciplinary power that reinforces and reflects a particular subjugating gendered role. While gendered, the discourse and

discursive practices of the breast cancer movement function through the rhetoric of risk which persuades women to monitor their breasts but which at the same time medicalises their bodies (Klawiter, 2008; Roberston, 2000).

The rhetoric of risk of breast cancer focuses on a woman's lifestyle choices, her female body, her genes and her environment, in order to encourage her to engage in body projects to prevent breast cancer. The attention to risk factors without reliable facts produces fear of the body, and, as mentioned earlier, the prevention of breast cancer (not yet accomplished by medicine, apart from prophylactic mastectomy) becomes synonymous with early detection, thus displacing responsibility for the disease from society to the individual. Through the rhetoric of risk, the breast cancer movement promotes the ideology of femininity by manipulating women to become complicit subjects in their subordination. Furthermore, the medical and public health directives, (also as yet unproven), to prevent breast cancer are the same directives to attain the white heterosexist ideal of beauty. The woman is thus re-inscribed into the traditional feminine role of caretaker (of her body), and femininity is not only preserved but produced, despite a disease that physically threatens a woman's most visible marker of her femininity, the breast (Desiderio, 2004).

### **Breast Cancer as a Threat to Female Roles, Identity, Femininity and Self-worth**

#### **The Gendered Discursive Objects of the Endangered Female Breast and Threatened Femininity**

Alcoff (2006) draws attention to the salience which particular bodily features have in our experiencing of our own bodies and the bodies of others – not as an objective anatomical body, but the body and its tasks - in which some aspects are more visible than others (Weiss, 1999). Importance of bodily sensations ensures that our body image is formed by the way the body is experienced and emotionally invested, rather than cognitively represented (Butler, 1993; Weiss, 1999). Awareness of our bodies is not neutral or purely cognitive (Butler, 1993).

The way we have of experiencing our bodies invests particular contours with emotional and affective salience. Some of our bodily zones and shapes become significant to us, while others are barely noticed. What shape the body is taken to have and the salience of that shape is therefore formed by affect, emotion and

desire, mediated by the relations we have with significant others, and the images we encounter in a public culture (Lennon, 2010, p. 17).

Adolescent girls and women invest in the catch-cry, “I must, I must, increase my bust”, and small “boobs” are considered just that – an embarrassing mistake (Walkerdine, 1990). Nursing mothers and their partners worry that breast feeding might sag or distend the breasts, and plastic surgery has enabled women to achieve breasts of choice (Weiss, 1999).

Like the prolific medical history, some of which was presented in Chapter Four, empirical research and the paper-trails left by women who experience breast cancer, are abundant and rich accounts of their passionate reactions to the disease when they perceive it as a threat to their overall well-being. Breast cancer is the cancer most studied in terms of its social and emotional aspects because of its threat to a part of the female body so rich in meaning (Breaden, 2008). Social, medical and psychological literature all record that the fear and stigma associated with cancer long hindered open dialogue about it (Baum, 1986; Cantor, 1993; Martensen, 1994), and continue to do so in modern society (Bloor & McIntosh, 1990). People afflicted by cancer, particularly women, and especially women with cancer affecting their sexual organs, commonly concealed, and today often initially conceal their disease from partners, other relatives and friends (Bloor & McIntosh, 1990; Hunter, et al., 2003; Morgan, 2003); Smith, et al., 2005). The predominant construction of cancer was that it was a mysterious, sinister, shameful disease, and fatal (Lerner, 2001, p.29).

The duration and embedded-ness of these constructions, when related to women, are epitomised in the traditional historical recordings of the behaviour of Queen Atossa over two thousand years ago. The first recorded ‘cure’ of breast cancer is credited by Herodotus the Greek historian (484-425 BCE) to Democêdes, a Greek slave who was called upon to treat the breast lesion of Queen Atossa of Persia (Mukherjee, 2010; Olson, 2002; Sandison, 1959). In her mid-30s Atossa discovered a ‘boil’ in her breast. It is recorded that as a woman she knew enough about breast disease to be fearful, and when the boil ruptured and discharged, and the lesion continued to grow, she went into hiding, staying away from her husband, and bathing only in private (Olson, 2002). Herodotus, the Greek historian, wrote that “so long as the sore was of no great size, she [Atossa] hid it through shame and made no mention of it to anyone” (Crawley, 1952, p. 118). Finally, with the growth engulfing much of her breast, and worried about sexual

castration, disfigurement, loss of her allure, and fearful of dying Atossa consulted Democêdes for medical assistance (Crawley, 1952).

This is the earliest recorded construction of women's fear of breast cancer, the shame involved with it, and the need to conceal its physical effects from one's partner and social group. Most women, whether they consider themselves feminist or not, have not thought about the complex relationships which exist between power, ideology, language and discourse at the micro- and macro-social level (Bordo, 1989; Code, 1991). Feminists argue that gendered discourse is a consequence of gendered socialisation, which gives rise to sexist behaviours. Femininity invokes a stereotype and is a central aspect of female gender performance. Because the human breast is so imbued with 'femaleness', it invokes particular types of behaviour to which most women conform (King, 2004). Atossa's discourse is important because it is the earliest and most enduring gendered construction of a woman's perception and experience of breast cancer. The prospect of pain, disfigurement and death is made even more cogent and fearsome when a part of the body so steeped in imagery such as the breast, is threatened by disease (Shilling 1993). Most women with breast cancer want to preserve as much of their breast as possible (Botteri, 2010; Morgan, 1998). Atossa has become emblematic of cancer sufferers through history. For example, in his history of cancer, *The Emperor of All Maladies*, Siddhartha Mukherjee (2010) imagines Atossa travelling through time. While the tumour stays the same, Atossa is positioned by ever-changing thinking and approaches about how to manage it.

### **Gendered 'Normalising' of the Female Body Treated for Breast Cancer**

The gender and psycho-oncological literature show that there can be significant emotional and social issues relating to breast cancer surgeries and treatments which amputate or disfigure breasts, thereby compromising threats to beauty, sexuality, and femininity (Holland, 2010; Holland & Weiss, 2010; Rosenbaum & Roos, 2000). For example, social pressures force some women suffering from breast cancer and those who have been treated to hide their bodies. This creates the paradox that once one has suffered from this paradigmatic woman's disease, one loses the socially valued signs of femininity. Breast cancer treatment, as previously described, can result in a marked physical alteration and a less-than-perfect body image (Greer, 1999). Its effects are framed in images and discursive constructions of the body as being corrupted, polluted, de-energised and desexualised – significant threats to femininity (Levin, 1999; McCarthy, 2002; Sontag, 1978; Tritter & Calnan, 2002).

Feminist writer Audre Lorde, writing of her own experiences of breast cancer in *The Cancer Journals* (1980) said, in a society “where the superficial is supreme, the idea that a woman can be beautiful and one-breasted is considered depraved, or at best, bizarre, a threat to ‘morale’ ” (p. 65). Such women do not possess what some have called ‘the official breast’ (Coco, 1994), ‘patriarchy’s ideal breasts’ (Ms, 1996), ‘the feminine beauty forms’ (Davis, 1991, 1995). The discourse of beauty is seen by some feminists as a controlling process, giving rise to feelings of inadequacy in women, poor self-confidence, distortion of body image, and lack of well-being due to a lack of perceived femininity (Coco, 1994). Some of these writers have created a new discourse about women’s bodies and health issues, arguing that women who have undergone a mastectomy, radical or partial, no longer need to feel self-conscious or ashamed that their breast has been amputated or is different to others’ (Gilbert, et al., 2010). Further, some feminists have taken exception to the increasing move by patients to have breast reconstruction after surgery (Morgan, 1998), considered an ‘atrocity’ rooted in a cultural obsession for women to remain sexually attractive to men. Prostheses are likewise considered cosmetic devices that place surgeons’ profit and denial of difference over women’s health and well-being (Bordo, 1989; Davis, 1991, 1995). The prosthesis is also seen as a symbol of the psycho-social issue faced by all breast cancer patients of the “silence and invisibility of [wishing] to be the same as before” (Lorde, 1980, p. 13), a strong sentiment commonly expressed by women (Gilbert et al., 2010; Hordern, 2008; Ussher, et al., 2012). Even further, Lorde (1980) and others have argued that breast reconstructions or the wearing of prostheses only serve to disempower women further by concealing those recovering from breast cancer “from each other and from themselves” (Lorde, 1980, pp. 52-53).

At the intersection of medical and gender discourses then, physicians contribute to the belief that women with one or no breasts are unnatural, and that women who undergo mastectomy are in need of further medical ‘treatment’. Mammoplasty or re-constructed breasts, and prosthesis after surgery, promote conformity to societal norms of beauty and femininity by continuing to advance the sexual stereotyping of body image, maintaining a visible distinction between the sexes. Forms of cosmetic surgery, or what some term ‘vanity’ reconstructions, ‘doing breast work’ (Phibbs, 1994) or ‘Venus envy’ (Haiken, 1997), perpetuate ‘otherness from males’ through the construction of artificial physical differences (Davis, 1995; Haiken, 1997; Morgan, 1998; Wilson, 1985), rather than being medically necessary. However, women themselves are active participants in

this process (Conrad, 1992) finding the regaining of their former body shape empowering and self-affirming (Desiderio, 2004).

Feminist scholars of disability have also highlighted the intersection of standards of beauty, gender and disability in the practices of 'image programmes' (Kendrick, 2008). Image programmes are specific types of psycho-social cancer services developed to help women address the appearance-related side effects of cancer treatment. They include medical and mastectomy 'boutiques', and other cosmetic and makeover programmes. Some writers on disability argue that the primary goal of image programmes is to 'normalise' female cancer patients by hiding the physical evidence of illness and by reconstructing women with cancer as physically attractive, heterosexual and not disabled. The recovery of femininity and a feminine appearance is seen as central to recovering health. As a result, image programmes take on a certain clinical legitimacy and become powerful reproducers of heterosexist and ableist discourses of gender and wellness (Campbell, 2009; Kendrick, 2008).

### **Breast Cancer as a Threat to Other Traditionally-Gendered Women's Roles**

Women's experiences of breast cancer go far beyond managing the *physical* issues of the disease (Holland & Lewis, 2000). The woman with breast cancer is positioned in a marginal group in relation to healthy society (Foucault, 1977a, 1978, 1984). As has been shown in the literature cited so far, not only is her physicality threatened, but also the roles she plays within that society. The discourse of identity is generally used in the context of role theory to refer to the demands experienced by women as a consequence of the many expectations about being a woman in contemporary societies (Wilkinson & Kitzinger, 1995). In addition to the demands of being a 'good' mother, maternal and domestic, a satisfactory sexual lover, 'whole' and 'sexy', and a responsible citizen, there are anxieties related to the actual withdrawal or departure of one's sexual partner, loss of income, compromised employment or future employment opportunities, health insurance issues, unmet needs, and uncompensated care arrangements (Holland, 1998).

Despite the medical 'truth' that breast cancer as a disease of women has been shown across the world to be borderless, within the gender and feminist discourses it continues in modern times to be depicted as a white middle-class women's disease, mirroring the dominant models of femininity in society. Most of these depictions are in women's magazines, fashion and the media (Black, 1995; McKay & Bonner, 1999; Lupton, 1994a). Today, the gendered and feminist gazes rest not solely upon the inert object of



the breast as in medicine, but rather the breast provides a starting point for a much broader observation of the many anxieties, fears, and reservations in a woman's life which arise from having breast cancer (Rosenbaum & Roos, 2000). This review shows that for women, a healthy body is tied to healthy sexuality and reproduction, and the efficient execution of expected female roles. Females have breasts with specific and expected functions. As with all subjectivity, if different aspects of one's identity are contradictory, or are experienced as being in conflict with other positions and/or expectations, there is a possibility of lowered self-esteem through a self-perceived lack of power or control. This is aligned in the psychological literature, and can be seen as a type of psychological discursive practice (Potter, 2012). A diseased or treated breast is linked to unhealthy sexual self-images, impaired sexual and breast-feeding functioning, (Hawkins, et al., 2009; Hordern, 2008; Ussher et al., 2012), and inefficient functioning in feminine positions and responsibilities. Most, if not all longitudinal studies examining adjustment to breast cancer, expose the pervasiveness of the cultural and gendered meanings of its impact on women's social interactions (Rosenbaum, 1994; Rosenbaum & Roos, 2000).

## **Summary**

In this chapter I present a review of key post-structural and Foucauldian literature which have explored the female body and breast cancer through the lenses of gender and feminism. The research shows three major themes. These encompass the gendered constructions of the woman and body and the sexualised and functional female breast; feminist constructions of breast cancer as a gendered and feminist event, with the female body as the unequal site of power and social control between the sexes; and that breast cancer can significantly compromise women's identity, femininity and self-worth, and their ability to function efficiently in their expected female roles.

Discursive constructions are greatly influenced by the historical epoch and prevailing public knowledge and attitudes (Foucault, 1972). Over aeons of time, the dominant focus on breast cancer has been medical, independent of its social context. While there have been (and are) others, these have been rendered silent or invisible. Gender and feminist literature show however, that there has been a gradual shift or superimposing in the localisation of disease and illness from the pathological to the subjective woman, locating her in a multi-dimensional gendered and social space. "The origin of the truth is that the attention of the gaze has been deflected from the pathological lesion to ...

more recently... the characteristics of the social space in which the body resides” (Nettleton, 1994, p. 84).

The female human breast has long been symbolically and discursively the intersection where female sexuality and ideal motherhood meet, and where sexed, gendered and feminist knowledge and power find expression. A woman’s breasts symbolise both motherhood, so central to women’s traditional identity, and female eroticism, likewise central to perspectives of sex role stereotypes. Breast cancer as a gendered discursive object is constructed as intimately linked with notions of womanhood, affecting a major bodily site that is the most powerful symbol and outward sign of femininity, but also the site of patriarchal power. Gendered constructions of the sexualised and functional female breast mean that the discovery of symptoms, diagnosis, treatment and recovery from breast cancer, compromise female gender identity, femininity and self-worth. While breast cancer is constructed by some as an ‘epidemic’ (Kasper & Ferguson, 2000), it can also position one as an outsider (Klawiter, 2008) - a citizen of “that other place” (Sontag, 1978, p.15).

In the second decade of the 21<sup>st</sup> century, breast cancer continues to hold the highest public and gendered profile of all illnesses in the media and in the popular press, stimulated by the Pink Ribbon symbol, Breast Cancer Awareness and fund raising events, and the brave one-, no-, or reconstructed breasted heroines who have “fought hard and fought back” (Novartis, 2011). Breast cancer will undoubtedly be, for some time yet anyway, ‘this year’s ‘sexy’ ‘chick’s disease’ (The On-Line Slang Dictionary, 2014), a sisterhood which transcends money, fame, ethnicity, time and space. However, while breast cancer continues to be a significant medical problem for women and for oncologists today, the under-estimated indelible emotional or psychological issues associated with it, just as critically, are yet to be addressed.

In the next chapter I begin the presentation of my research findings which underpin my argument. Over the next four chapters I analyse the discourses identified in the interview data collected from women and health professional participants and generated for the purposes of the study. I start in the next chapter with discourses constructing the discovery of breast cancer symptoms, and move in subsequent chapters to the participants’ constructions of diagnosis, treatment and recovery.

## **CHAPTER SIX: THE DISCURSIVE FIELD OF DISCOVERY**

### **Introduction**

This is the first chapter of four in which I present my findings. As I explained in Chapter Three, I used a semi-structured model for interviewing. While this gave some structure to my questioning, the participants did not talk in a linear way, but rather more randomly. They chose to describe particular experiences, and to follow lines of narrative which were obviously the most significant for them. These roughly aligned to ‘stages’ within their breast cancer experience. In order for me to identify the emerging discourses and subjectivities across the whole corpus of the material, I elected to use these as my findings chapters’ headings. These stages were: discovery of symptoms, diagnosis, treatment, and recovery. Each of the stages provided a different type of discursive focus on the participants’ experiences across the whole event, during which different speakers moved in and out, and different roles and subjectivities were played out. In this chapter, I identify and analyse the discourses which I contend are strongly indicated in the women’s experience of the initial discovery of bodily symptoms, and by which they interpreted the possibility of breast cancer.

I argue that is the medical and public health discourses which bring to the fore the discovery of difference in breast tissue and its construction as a ‘lump’ as symptomatic of breast cancer for the women, and as such, a threat to the women’s lives and health. However, when analysing the women’s responses to the discovery of a lump or new or unusual thickening in the tissue of the breast, under whatever circumstances this occurred, it was important for me to keep in mind that the construction by one discourse of that event would undoubtedly invoke various other discourses (Foucault, 1972; Parker, 1992, 1999). According to King’s (1982) review of historical medical thinking, meaning comes for both the patient and the health professional when a confirmed diagnosis is made. The analysis presented in this chapter showed that while dominant, the women made meanings of their symptoms in ways other than those so strongly legitimised by the medical discourse.

### **The Medical Discourse**

I define the medical discourse in this study as that which constructs a discursive object through the medical language and text of the science and practice of the diagnosis and treatment of disease – in the specific sense of healing, curing or therapy. The medical

discourse excludes a critical appraisal of the social context of illness or disease. The public health discourse encompasses over-arching government-derived policies, campaigns, neo-liberal health promotions and knowledge, and expectations for behaviour implemented for the general prevention and alleviation of disease (Foucault, 1991; Osborne, 1997). In this study,

I include the public health discourse within the medical discourse umbrella because medicine is the umbrella under which public health sits (Breslow, 2002; Schneider & Lilienfeld, 2008; Turnock, 2009), however where one regime is specifically cited, I use the singular term medicine or public health.

### **Medicine's Discursive Object – A Lump**

The medical discourse makes the distinction between what is understood by 'sign' and by 'symptom'. Medical discourse commonly distinguishes signs from symptoms (Burnurn, 1993; Malterud, 1999). While both are something abnormal and relevant to a potential medical condition, a symptom is constructed as that which is discovered, experienced and reported by the person seeking medical advice, whereas a sign is said to be detected by the physician during examination of that person (Weatherall, 1996). The distinction between a sign and a symptom is a product of the medical discourse, and use of either term immediately infers the deployment of the hegemony of that medical discourse – its dominance and authority to interpret or 'read' the body, and to give that reading meaning. The term 'patient' is both a product and discursive practice of the discourse, and a person is constructed by it as a 'patient', regardless of a confirmed diagnosis or otherwise. I expand on the notions of the identity and subjectivity of the medical patient in the Chapter Seven.

On its discovery, the lump in the breast was constructed by the women, their partners and GPs, as abnormal and highly probable to be cancer.

*I felt a lump. I knew what it might be. Hesitatingly I felt again. Definitely a lump. Of course you tend to think of breast cancer. Cancer is the first thing you think of when you get a lump. You hear that sort of thing talked about all the time. You quite automatically think that way. I hoped that I had found it early enough.*

Carol

*“It’s a lump,” I thought. “Mary, you have cancer, capital B, capital C, Breast Cancer”. The possibility that that lump might mean I had cancer took over in my head.*

Mary

Carol and Mary’s excerpts were illustrative of the discovery of a lump in the breast as a medical event - the construction of a breast symptom as a physiological ‘alarm’, and of breast cancer as a lethal disease. All of these concepts are products of the medical discourse, and Carol drew immediately on the cancer construction, so engrained in our culture that a lump and cancer are synonymous, and are commonly talked about in this way. Mary spoke in the modern idiom of cancer as ‘the big C’. Such talk reflects medicine and public health’s constructions of a breast lump, and of the size of the problem of cancer. Carol’s excerpt also identified the discovery of a lump in the breast as a public health event in her reference to how commonly breast cancer is talked about. Her hope and reliance on early detection, was a result of the powerful and pervasive public health discursive practices of annual campaigns and mammography screening programmes, which encourage women to participate in regular breast screenings. The associated medical ‘truth’ invested in by women is that early detection means timely treatment and lives saved.

With these sets of definitions, it was obvious that there was some overlap – certain things qualified for some of the women as both a sign and as a symptom. The medical discourse has created a distinction on the basis of a medical knowledge which values the objective over the subjective. The dual construction of the lump qualifying both as a symptom and a sign is a post-structural binary, or two types of ‘truths’ (Foucault, 1978). At this early stage of the breast cancer experience, it was the place or setting of discovery, whether in the privacy of the woman’s home, or under the medical gaze of a health professional or oncological technology, which determined whether a lump was constructed as a symptom or as a sign. In general, most women talk about the discovery of their lump or symptom as being ‘found’, ‘felt’ or ‘discovered’. In contrast professionals and technology ‘detect’ or pinpoint signs. Carol and Mary’s relationship to the lump, as opposed to medicine’s, depicted and juxtaposed the subject positions of the women and the health professionals.

### **The Subject Position of the Woman Medically at Risk**

Use of the word 'risk' in medical journals has reached 'epidemic proportions' (Skolbekken, 1995). One of the main medical functions of the discourse of 'risk epidemic' is to predict disease and death, and gain control over disease thereby confirming faith in medical science, scientific legitimacy, objectivity and expertise (Lupton, 1995). The public health discourse positions women as being at risk of breast cancer and death. The offering by public health and the taking up by women of this position is again the result of the pervasiveness of the medical construction of risk (Burr, 2003).

*While this lump seemed to come out of nowhere, I was prepared for the fact that it could be me whose number came up. It seemed like a lottery, the luckiness or unluckiness of the draw, but I guess I knew all along that I, like most other women, was at risk of developing a lump, and that the lump could mean cancer. I felt frightened when I discovered just how much at risk my life was.*

Jo

Jo positioned herself as a subject at risk of breast cancer. She found the lump herself, and knowing that she was at risk, sought a medical consultation with her GP immediately. The medical discourse tends to construct individuals as attuned to a "rationalist understanding of reality" implicit in the "discourse of risk" in which things do not happen without warning and "unfortunate events are deemed to be both predictable and avoidable" (Lupton, 1995, p. 79). The medical and public health discourses construct a disease like breast cancer, as one that can strike at any time. All women - young, middle-aged, older, married or single, mothers or without children - are constructed by medical discourse as being at risk, and finding oneself in a 'risky' position can cause considerable anxiety for some women. The lump is an object of possible danger, and Jo was immediately suspicious, and felt unlucky and fearful.

### **The Subjectivity of the Woman and the Health Professional Made Anxious by Medical and Public Health Discourses**

Risk has come to stand as one of the focal points of feelings of fear, anxiety and uncertainty Lupton (1999a; 1999b). There is a modern climate of risk which is characterised by an awareness and acknowledgement of 'high consequence' risks. This can be seen in the medical discourse which describes breast cancer as occurring without warning, and which universally constructs the consequences of undiagnosed or

untreated breast cancer as deadly (Lipmann, 2011). By detailing the risks of succumbing to diseases like breast cancer, the medical discourse increased the likelihood that the discovery of a lump would produce significant unease in the women in this study.

*I hoped that I just had a lump. I got terribly worried, panic-stricken actually. Fear gripped me like a vice. I was afraid and just didn't want to know. I didn't want information about how that lump could harm me. I didn't want anyone to talk to me about it because I was afraid of what I would hear. I was afraid of what that lump might mean.*

Anne

*Feelings flooded me. I tried to stay calm, but an inner voice was pounding in my ears. I was very, very frightened. I tried to keep myself busy to push away the fear. I tried to keep my mind off the lump, that white image on the mammography screen, but my thoughts were in top gear, and my body was stone-dead.*

Jessie

Anne found the lump herself, and Jessie's was detected by mammography. Anne was very focussed on the lump, and believed deeply in its potential to cause her great injury. Jessie spoke of being overwhelmed and "flooded" by emotions of fear from an "inner voice", and seemed paralysed by the discovery of the lump. Fear itself is a discursive construct, and is identified by psychology as playing a key role in 21<sup>st</sup> century consciousness (Glassner, 2004a, 2004b). Increasingly, people seem to engage in narratives of fear to make sense of their own and others' experiences. Fear is not simply associated with high-profile catastrophic threats such as 'Acts of God', terrorist attacks, global warming, AIDS or a potential flu pandemic. Rather, as many academics have pointed out, and Anne and Jessie illustrate, there are also the 'quiet fears' of everyday life (Altheide, 2002) such as being diagnosed with a terminal disease, becoming disabled or disfigured, dying or becoming bereaved. Both Anne and Jessie assumed the subjectivities of women made very fearful by the medical construction of a lump in the breast, and illustrated the lived tensions within this identity.

The subject position of surveyor and assessor of a woman's body is opened up by the medical discourse for those professionals who conduct breast examinations on women, and women have little choice but to submit to this form of medical surveillance. As the possessor of knowledge about women's bodies, the practitioner has the authority and

responsibility to take this knowledge for further scientific testing. In doing so, the act of performing this type of examination caused some of the doctors in the study to feel anxious.

*When I am conducting breast examinations, I always feel a little panicky if I discern a lump or thickening in a woman's breast. In my experience it almost always means cancer. Until things are confirmed, or even better should I say, when the results are negative, there is always a feeling of unease related to that woman.*

Tony, GP

Tony's comment demonstrated his deployment of the medical discourse which constructs a lump in the breast as a signal to health professionals of a threat of cancer in women. Tony identified feeling alarmed at first, and a feeling of anxiety which remained with him until a diagnosis was confirmed. His sensing that the lump would almost certainly mean cancer reflected the strength of medicine's medicalisation of life in general. The promulgation of medical statements about symptoms and diseases has led some writers to consider that "the unmedicalised body is a sheer impossibility" (Harding, 1997, p. 145), especially a female body (Harding, 1997; Lupton, 1997; McNay, 1992; Ussher, 2006, 2007). Tony adopted both medical and gender discourses in his construction of the female body as being medically at risk and in his use of the word woman rather than patient. But his words also revealed a health professional who felt anxious about his female patient, knowing that what was to follow for her was a difficult diagnostic and treatment process.

### **The Discursive Practices of the Woman Constructed as Responsible by Medical and Public Health Discourses**

Medical and public health discourses have considerable power to motivate behaviour because choices are shaped and limited by them. While some of the women initially kept knowledge of the existence of the lump to themselves, and delayed investigation (Andersen et al., 2009; Bish et al., 2005; de Nooijer et al., 2003; Macleod et al., 2009; Meechan et al., 2003; Morgan, 2003; Smith et al., 2005), eventually all of them acted in a way that is considered by medical and public health to be that expected of the responsible citizen (Osborne, 1997; Petersen, 1997).

*Something inside kept reassuring me that delaying any diagnosis or treatment for a little while wouldn't compromise my chances. I trusted this "something",*



*but my common-sense told me to take no chances. I guess for a little while anyway, I took a risk, but in the end, about a week later, I went to see my doctor.*

Diane

*I took immediate action. Throughout my life I like to think that I'm an action sort of person. I'm a fighter and an information-seeker, and it just seemed the right thing to do. No point in delaying the inevitable. There was information out there about myself that I desperately needed. By choosing to seek that information I felt as if I had a level of control... that I was in charge of myself.*

Rose

The public health discourse has constructed new politics of citizenship, with an associated greater emphasis on 'duties implied by rights' (Roche, 1992). Choices of behaviour result in the subjectivities of what Foucault (1973) and Petersen (1997) generally call the 'responsible' and 'irresponsible' citizen, which are societal descriptions and moral judgements of how one should or should not behave under certain circumstances. Being a healthy, responsible citizen thus entails new kinds of detailed work on the self (Martin et al., 1988). As Foucault (1982b) described, the activation of the responsible woman is seated in the power tactics of the self, linked strongly to the centralised practice of governing the individual. Emphasis on risk factors which are within the control of the individual contributes to the confirmation of the active citizen, the self who can be, and who *ought* to be in control of oneself. The responsibility and common-sense of self-surveillance practices separate the vigilant from the non-vigilant woman, protect the former from powerlessness, and bring her power and control.

Diane and Rose's excerpts were clear illustrations of the two different discursive practices enacted by some of the women on the discovery of a lump in their breast. Diane was taking no chances, and Rose felt that she knew the "right" course of action. Identifying themselves as being at risk, neither was prepared to gamble on the hope that the lump would be benign. While Diane initially delayed or resisted, Rose did not. Both of them were immediately constructing specific contexts of personal risk, and enacting in an individual way, what Osborne (1997) terms 'responsibilisation', by which the responsible citizen practises sensible self-management. This is the neo-liberalist ideology of responsible care of the self, shown in Diane and Rose's belief that it was their duty to take responsibility for their own general health, and to take action when

they perceived it was failing. “Potential patients are to be responsible for being entrepreneurs of their own health”, (Osborne, 1997, p. 186). In the face of apparent increasing uncertainty, Diane and Rose were compelled by medical and public health constructions of the breast lump to engage in a process of personal decision-making and personal conduct, the outcomes of which are considered by society at large as either ‘responsible’ or ‘irresponsible’ (Petersen, 1997).

The medical and public health constructions of breast cancer as a significant disease of women, has thus brought to notice a population of women whose health is endangered in a common, though individualised way, through the construction of risk. Giddens (1991), Beck (1992), and Lupton (1993, 1999a, 1999b), describe how responsible individuals today think more about the personal risks they take and of the possible risks to them inherent in modern society. For these writers, risk is central in 21<sup>st</sup> century life and has become a key element in the calculations of the self, and the calculated risks one takes with oneself. It was probably not surprising therefore, that Diane and Rose were constantly in a state of readiness by their alertness to the possibility of developing breast cancer at any time in their lives. Their accounts provide valuable insight into the calculations of the self, or the calculations of risk a woman might take when breast symptoms first become evident. The effect of Foucault’s technology of power, “the coercion of normalisation” (Foucault, 1977, p. 1637) can be seen in the actions the two women took. The public health discourse coerced them, by positioning them as being at risk of developing breast cancer, to seek a medical consultation rather than some other form of meaning-making.

The above examples show Foucault’s (1991) concept of governmentality at work. As described in Chapter Two, governmentality refers to certain specific techniques within public health, health education and health care developed over time by governments and the state in order to exercise power over populations as a whole. In today’s world, women are such a population, constructed by the medical and public health discourses as being much at risk of developing breast cancer. As previously iterated, medical statistics show that a significant proportion of the female population is defined as being at an at-risk state of developing breast cancer. Medical, public health and health education discourses serve as constant reminders to the women of this ‘truth’ (Armstrong, 1995; Gastaldo, 1997; Petersen, 1996).

Medical and social histories propose that breast cancer became the quintessential women's health issue from the 1990s. This was largely as the result of media attention and calls from advocacy groups for the acceptance of breast cancer as an issue of sex and gender equity (Kasper & Ferguson, 2000). This vastly increased attention brought breast cancer much more into the public gaze, and also brought with it not only an onus on the health care system to address issues relating to the diagnosis, treatment and care of women with breast cancer, but also on women themselves to be more vigilant about their own symptoms.

*I felt a lump, and I knew enough about breast cancer to realise that I could be in deep trouble. Breast cancer is everywhere. Pink ribbon this, and pink ribbon that. It's a world-wide, universal pink ribbon. I think that for women generally the colour pink serves as a constant reminder that we are all at risk of this disease. Even to the pink macaroon biscuits I have with my cup of tea. Can you believe that?*

Stephanie

Foucault (1980) saw the status of one's health as being a form of policing or surveillance through discourse. Public health discourse contains strong messages that women take responsibility for breast self-examinations or for having regular clinical examinations, in order to pre-empt the development of a serious disease state which would become a larger problem for society to address. Stephanie's comment revealed that New Zealand's women's daily lives are flooded with Pink Ribbon fund-raising through cause-related marketing ranging from women's razors to 'Pink Breakfasts'. Countless women's magazines and television programmes present breast cancer in its most positive and negative lights. As a result, women are inundated with messages which implore them to not only keep thinking *about* breast cancer, but *how* they should think about it. The dominance and pervasiveness of the medical and public health constructions of breast cancer were very evident for Stephanie, largely through their perpetuation of the incidence of breast cancer as an 'epidemic' (Kasper & Ferguson, 2000; Lantz & Booth, 1998; Mukherjea, 2010), or 'plague' (Riley, 2006). There were sufficient Pink Ribbons visible in her world, for Stephanie to be constantly aware of the health of her breasts, and of her potential susceptibility to breast cancer.

## Medical and Public Health Techniques of Power in Discovery

The word ‘surveillance’ in everyday language comes from the French meaning ‘to watch over’. It has come to further mean the close observation or supervision of a person, object or group. Within these definitions are connotations of shadowing, investigating, scrutinising, and of the metaphorical Greek giant Argus who had one hundred eyes... an ever-present, inescapable watcher, guard and inspector. A major part of Foucault’s (1977) concept of surveillance, as described in Chapter Two, pertained to the focus on the body and related questions of power. At this point in the breast cancer experience, the women had engaged in practices of self-surveillance for symptoms. While anxiety-provoking, they had conducted breast self-examinations, had GP examinations and mammography. Now, with the discovery of a definite symptom - a lump in the breast, all of the women participants turned to medical surveillance rather than to other approaches, for diagnosis.

Medical experts advise women to seek breast screening services, but through their deployment of the construct of risk, medical and public health discourses also call upon women whose bodies are at risk of disease or dying to “gaze upon themselves” (Bunton & Petersen, 1997, p. 7), and make themselves objects of self-surveillance. In these situations where the women themselves and their bodies are turned into objects, self-surveillance emerges as a practice of self-control (Eckermann, 1997).

*I knew from my doctor and from things I had read about breast cancer, that it was important to conduct self-examinations.*

Mary

*I had done self-exams. I didn’t want to. Most women I’ve talked to don’t want to because they ... we ... are afraid of what we might feel. I was fearful of finding something, fingers digging into my breasts and that. You could have felt anything.*

Stephanie

*So I was referred for a mammogram ... the standard next step it seemed. I needed to know, and mammography and biopsy were the ways to go my doctor told me. So, in fear and trembling, I went.*

Carol

Mary, in her conducting of breast self-examinations, was an example of Foucault’s active, rational citizen, the self-observer who monitored her own body and lifestyle for

any signs of abnormality, and who sought information in attempts to retrieve her 'normal' body. The discovery of symptoms, whether by accident or by intended examination, and Mary's individual response to this palpable object, was an example from Foucault of the collective tactical power of both medicine and public health on issues for the women participants relating to self-surveillance and self-governance. There was an element of coercion on Mary to take responsibility for self-care, which resonates generally throughout medical and public health discourses relating to breast cancer. Foucault's (1973) notion of the 'normative coercion' of medicine can be applied to Mary's comment. By 'coercive' Foucault meant the ways in which medicine disciplined Mary and exercised forms of surveillance over her everyday life in such a way that her actions were both produced and constrained by them. Mary had assigned herself a meaningful frame of reference where she felt most powerful, and had taken opportunities for proactivity rather than resistance or inaction (Bunton & Petersen, 1997).

Mary and Stephanie gave voice to the 'responsible woman' in their conducting of self-examinations, but Stephanie also revealed the anxiety she experienced in doing so. This related to the balance between her calculation of personal risk, and the duress she felt to turn to medicine to make meaning of 'the lump'. Carol, equally fearful, submitted to medical surveillance because her doctor told her to. One of the most significant factors contributing to the women's feelings of anxiety relating to breast cancer was the pressure they felt they were under from medicine and public health to be constantly vigilant towards breast symptoms, and to regularly monitor themselves and be monitored by medical practices and technology. The possibility of the discovery of a breast lump or other symptoms, as seen in Stephanie's excerpt, was that the breast had to 'be watched' or surveyed as a risky site within the female body. I explore the gender discourse of the 'risky female body' later in this chapter, but its emergence at this point showed how the interplay of medical and gendered constructions produced the discursive constructions of the women's emotional reactions and actions.

While Foucault has been criticised for his inattention to gender in his analyses of the body and self, his concepts are very applicable to the analysis of the regulation of Stephanie and Carol through the 'bio-power' of what Armstrong (1995) terms 'surveillance medicine'. Public health and health education date from the turn of the 20<sup>th</sup> century when the medical paradigm underwent a shift. The traditional history of breast cancer shows that the predominant model in the 19<sup>th</sup> century was hospital

medicine, concentrating on symptoms and signs that together configured a pathological state. This model has maintained its influence into the 21<sup>st</sup> century, and the paradigm of surveillance medicine continues to construct and create new concepts of illness and normality. The concept of watchfulness or surveillance by medicine, moved the attention of medicine from pathological bodies to each and every member of the population, and, as I described earlier, in doing so the normalising categories of health and illness gave higher priority to the notion of ‘risk’. Stephanie and Carol, finding themselves in a position of risk, engaged in the discursive practices of the responsible citizen, compelled by medical/public health to conduct breast self-examinations or to seek clinical examinations, both of which were emotionally difficult forms of self-surveillance for them.

Both Stephanie and Carol’s reactions were examples of the effect of Foucault’s “coercive technologies of behaviour” (Foucault, 1973, p. 1637). Technologies of behaviour produce both the observed – Stephanie and Carol, and the observers – themselves, their GPs and medical technology. Public health/medical technologies of power are instruments of “perpetual assessment” (Foucault, 1973, p. 1637), and it is these instruments of perpetual panoptical assessment that lend themselves so powerfully to the coercion experienced by both these women. The medical profession’s task as “technicians of behaviour” is to produce Stephanie’s and Carol’s bodies that are both “docile and capable” (Foucault, 1973, p. 1637). That is, there must be experts of possessors of knowledge like Carol’s GP and mammography technology, who/which observed or examined her in order to ‘correct’ her. Their so doing produced functional and responsible citizens of society. The application of the concept of surveillance to medicine, described by Foucault (1980) in his later work, was an extension of the medical or clinical gaze, and has facilitated the understanding of the relationship between knowledge and the body. Foucault wrote of the body as the target of the medical gaze and of medicine’s self-appointed right to establish rules and protocols for its management or “governmentality” (Foucault, 1991).

Having a mammogram every two years improves a woman’s chances of surviving breast cancer. Early detection is your best protection.

Ministry of Health, New Zealand Government, (2013)  
BreastScreen Aotearoa pamphlet

Consequently, Stephanie and Carol, believing themselves to be being constantly assessed, modified their behaviour to fit into accepted ‘norms’ of behaviour. Foucault

asserted that these technologies of behaviour function as instruments of perpetual assessment through networks of permanent observation (Foucault, 1973, pp 1637-38), such as public health campaigns for regular breast screening and early detection of breast lumps. That is, the power of normalisation was seen in Stephanie and Carol's allowing of themselves to be observed, thus succumbing to the societal 'norms' of behaviour of responsible women, with the collective intention of maintaining disease free breasts. This tactic of power over Stephanie and Carol occurred at a subtle level however because its normalising was invisible.

Stephanie and Carol, by their very sex as female, were women with breasts, and thus at risk of developing breast lumps. Because of their sex, they were under surveillance both by public health and medical strategies of power, and by their engagement in their own self-surveillance and self-regulation. They were self-regulating because if they had deviated from the norms of behaviour expected by society as responsible (that is, not conducting breast self-examinations, not having GP breast examinations, and regular screening by mammography, and further, not seeking a medical diagnosis when a lump was discovered), they would be considered to be engaging in abnormal or deviant behaviour. In this way, these women with breast symptoms, because of their sex, and expected gender roles, became themselves a normalising power. As Foucault asserted, "the judges of normality are present everywhere" (Foucault, 1973, p. 1645). In *Discipline and Punish* (1977) Foucault talked of normalisation as the moulding of people into 'normal' as opposed to 'abnormal' forms. Governmentality is the process by which a society encourages its people to regulate and achieve his or her own conformity with the established rules. It is precisely because of this powerful observational function that Stephanie and Carol were forced to gain knowledge about breast cancer and their own bodies, and were made to be normal *female* citizens, functioning responsibly within society. It was here that gender surfaced as the second dominant discourse in the construction of the breast cancer experience.

### **The Gender Discourse**

Despite criticisms of Foucault's lack of attention to gender, his work emphatically problematised what has come to be understood as the established object of most female-focused, feminist analyses and gendered discourses – the problematic "sexed" female body (Bunton & Petersen, 1997, p. 6; Birke, 2000; Foucault, 1998; Ussher, 2007). Significant areas of women's bodily experiences have been, and are progressively subjected to many and varied techniques of medical surveillance. In the following

section of this chapter, I use gendered representations of the discovery of a lump in the breast as the central categories of discourse analysis. Gender discourse overlies the sex discourse's construction of a lump in the breast through the classification of the body as female as opposed to male, neutered or common.

Years of primarily sociological and anthropological research have revealed that the interpretation of bodily symptoms is deeply embedded within a social, cultural and gendered reality (Radley, 1994; Martinez-Hernández, 2000; Andersen et al, 2009; Butler, 1990). When applied to breast cancer, American sociologist Irving Zola's (1966, 1973) analyses of patients' presenting complaints illustrated that women experience and understand symptoms of breast cancer in relation to their specific sociocultural and gendered context at that given time. Post-structuralist feminist philosopher Judith Butler (1990), made little distinction between sex and gender, and interpreted them as social and cultural constructions. These discursive constructions presuppose certain roles and behaviours by subjects' performing of specific stylised actions. Such discursive practices maintain the appearance in subjects of the core gender, sex and sexuality which gender discourse itself produces (Butler, 1990).

### **The Sexed Discursive Object – The Woman with a Lump**

The woman with a lump discovered in her breast, was the discursive object of the sex discourse. The lump was constructed by sex. This construction shifted the gaze from the pathological and medical construction of the lump and its location within *a* body, to its site within a *female* body, with a focus on the sex of the lump's owner – the woman.

*I wasn't surprised when my doctor felt a lump. As a woman you sort of expect that this might happen. The statistics for breast cancer are high, so why not me?*

Mimi

Mimi's comment, that she was not surprised when a lump was discovered, reflected a form of anticipation or probability that this could happen to her solely because of her gender. Sexual difference is a construct of society, used to enforce the distinctions made between what is assumed to be female and male, and the attribution of specific sex-related characteristics, such as females developing lumps in breasts. Being female is the most important risk factor for breast cancer (American Cancer Society, 2013). Mimi's mention of statistics emphasised the construction of the breast lump as synonymous with a 'woman's disease'. As stated earlier, one New Zealand woman in eight will



develop breast cancer at some point in their lives, so “why not me?” Mimi thought. The combined statistics for the discovery of a lump in the female breast, whether benign or malignant, are obviously even higher, and some lumps are undiagnosed. Such statistics are biologically and overwhelmingly sex-biased. A lump was a “problem” for Mimi, as identified in Foucault’s (1984, 1991) analyses of the bio-politics of health and populations or groups, such as women at risk of developing breast cancer, “With its numerical variables of space and chronology, longevity and health, [breast cancer emerges] not only as a problem but as an object of [female] surveillance, analysis, intervention, modification etc” (Foucault, 1980, p. 171).

### **The Gendered Subject Position of the Woman at Risk in 21<sup>st</sup> Century New Zealand Society – The ‘Risky Female’**

Changes in breast tissue were not only related to the individual woman, but evolved and were defined in the specific places in which she was situated. How the women in this study established the relations between their symptoms and the possibility of breast cancer was strongly influenced by their specific social and cultural context. There were significant consistencies in the subject positions or roles taken up by the women on the discovery of a breast lump or other symptoms. These were generally, although not entirely, constructed as female, such as the role of mother, or the role of sexual partner, and which incorporated a critical construction of the sexual nature of the breast.

*I knew something was wrong. As a wife and mother I felt that my life was threatened ... the happiness and security we knew as a family was threatened.*

Rose

*My partner found the lump, and said: “What the hell’s this?” My God! Just at the point when we were enjoying each other’s bodies so much! My mind leapt forward in a strange sort of way to thinking ... this lump could bugger things up in this department!*

Bev

Traditional social, cultural and gendered histories document an ageless obsession with the whole woman and the perfect female breast (Greer, 1999). Aesthetic expectations of the female breast are constructions of how women’s bodies are perceived by society – how they should be, and the functions they should perform (Ussher, 1989, 2006, 2007). There is a cultural obsession with the female breast. Rose and Bev, and Bev’s male partner, all knew enough about the symptoms of cancer to be immediately aware that a palpable lump in the breast was abnormal, and signalled something threatening.

The bodily symptom of a lump in the breast is a social construction because it is embodied. It was certainly a tangible experience for the women in this study. Symptoms are also constructions that are made meaningful by the ways they are interpreted by society. Bev and Rose were engaging in a reading of the lump which was influenced by their individual gendered subject positioning as a female mother or lover. Both Bev and Rose had suspected that “something was wrong” within their breasts before seeking a medical consultation. As women with breast lumps, they constructed the lumps as problematic even before the point of further medical investigation. This is what some psychologists call ‘symptom interpretive’ processing (Radley, 1994), because it provides women in such a position with an understanding of how to manage their identity and social obligations within their social arenas at the time (Hay, 2008). Rose was fearful of what the lump might mean to her position of mother within her family. Bev, on the other hand, interpreted the discovery of a lump not as a danger to her life, but rather as an imminent threat to the quality of physical intimacy after cancer (Gilbert et al, 2010; Hawkins et al., 2009; Ussher et al., 2012), thus affecting her relationship with her partner and their enjoyment of sexual activity. Bev’s expressed fears also revealed that the discovery of symptoms was not only related to her as an individual woman, but was also defined in the very specific situation of sexual activity. Bev’s breasts were constructed as sexual objects, objects of the male gaze. Both Rose and Bev were alert to the possibility that their current status as healthy women might suddenly change, and both were assuming the identities of women who had much at risk. This was a position forced upon them by the gendered discursive construction of a suspicious lump in the female breast.

### **The Gendered Subjectivity of the Anxious Woman**

All of the women in this study were acutely aware of the possible meaning of a breast lump, and became alarmed on its discovery. As a result of their identification with such an at-risk group because they were female, they assumed the gendered subjectivity of the anxious woman.

*I felt very alone. I felt a great weight of loneliness. And I became extremely anxious. This anxiety stayed with me throughout the whole process. My heart started to pound, and almost instantaneously I had flash-backs to my aunt on her death-bed, dying not an easy death, from breast cancer, some years ago.*

Anne

Anne demonstrated her initial strong emotional response on the discovery of symptoms as one that she identified as fear. She was immediately suspicious, and experienced the classic physiological reaction associated with fear, the pounding heart. Significantly, she talked about the phenomenon of flashback or an involuntary memory of the anguishing death from breast cancer of a female relative. Her anxiety was related to the possibility that she, like her aunt, might die. Her association of her aunt with breast cancer revealed the deeply gendered embedment of the femaleness of the lump, and inferred female and familial genetics. Such was the prevalence of the gendered discourse of breast symptoms signalling significant danger to health and life that the women were instantly alerted and alarmed. Images of illness and health surrounded them, but as seen, their perceptions of illness were not limited solely to the domain of medicine. It was likely that they had encountered representations of illness and health in many places, not just in hospitals and clinics, but also in TV series, films and paintings, newspapers, literature, advertisements, poetry, music, and sermons (Lupton, 1994a; Roy, 2008). Anne was like all women who identify with the narrative expressions of pain, hope and fear in autobiographies, families and social networks, and on the Internet. Breast cancer as a disease of women is very well known in the Western world, and the discovery of symptoms conjured up for the women cited in this section, anxieties about threats of disruption to their lives as lover, mother, daughter. Fear was also generated in women like Anne, the genetically-related niece. Breast cancer did not occur in a vacuum for these women. Suddenly there was the threat of mortality, the possibility of the illness itself, and great uncertainty.

Anne's identity, like Rose and Bev's, of being at risk and as a result being anxious, was shaped by a gendered discursive script which instructed them how to respond to threats to their well-being as women.

Anne's comment also provided another important insight into the extent to which these experiences were described by some of the women as so very individual and personal. Anne talked about the loneliness inherent in her inability or unwillingness to reach out to others at such a troubled time. Despite her fears, Anne proceeded on her individual, solitary and reactive pathway. This is what Fitts (1999) described as the staunch individuality of women who are ill typically characterised in Western cultures by "...our unfortunate belief in the strength of the individual self, rather than a more communitarian model of interaction, [which] depicts disease as a social phenomenon" (p. 14).

One of the health professional's views on women's responses to the threat of a lump constructed women as emotional, and she drew on the psychology of fear to make her point.

*When a woman becomes aware of something in her body which she consciously or unconsciously connects with cancer, (most especially like a lump in the breast), she becomes incredibly frightened and feels that her life, or the way her life is at the moment, is threatened. The feelings awakened are sometimes so intolerable that she acts contrary to her usual common sense.*

Clare, Psycho-oncologist

In general, the women's comments made it clear that the process of help-seeking was very complex (Andersen et al., 2009; Bish et al., 2005; de Nooijer et al., 2003; Meechan et al., Morgan, 2003; Smith et al.). How they recognised, interpreted and responded was very subjective and individual, and they did not necessarily behave in expected ways (Morgan, 2003). The lump individualised and disciplined them, and the discursive practices in which they engaged were not only greatly influenced by medical factors, but also by their perceptions of risk to their perceived female roles.

### **The Gendered Discursive Practices of the 'Responsible' and 'Irresponsible' Woman**

Wanting to 'do the right thing', but being afraid to so is what Eckermann, (1997) calls 'a defiance of prescriptions of normality'. Drawing on Foucault (1973, 1977), she contended that when people carefully evaluate their precarious settings they "tend to become either docile subjects or rebellious subjects" (Eckermann, 1997, p. 157). What the women in this study did and did not do at the time of the initial discovery, or the discursive practices enacted by them, varied in their individual attempts to explain, rationalise and manage the meaning of the lump for themselves and for their significant others. Language was an important part of this process of self-evaluation and self-monitoring, and, quoting them, words like "guilt" and "blame" were commonly used. Such discursive practices provide some understanding of why they represented themselves in the contradictory ways that they did. Some of the women made rationalisations of "scarring from an earlier knock"; "fatty deposit"; "time of the month"; "there are so many irregularities in the breast", and other justifications of plausible reasons for the lump. Biological and psychological theories show that fear engenders such rationalisations, with associated behavioural responses of either 'fight or flight' – in this case, act or remain inert.

## The Women Who Delayed

Some of the women did not seek a medical consultation quickly after the discovery of symptoms. This was because, for them, a lump in the breast had been discursively constructed widely as something very threatening (Andersen et al., 2009; Bish et al., 2005; de Nooijer et al., 2003; Macleod et al., 2009; Meechan et al., 2003; Morgan, 2003; Smith et al., 2005). As a result, that threat hampered or impeded their immediate action. The women who delayed were positioned at the margins of both the medical and gender discourses, being constructed simultaneously as women medically at risk and as risky social females (Macleod et al., 2009).

*I found that for some reason I was resistant to finding out 'the truth', so I waited five weeks before I was strong enough in my head to confront the lump head-on. I comforted myself by thinking (well actually hoping like hell) that the lump was just an infection, a bump, a bruise that I had got going about my daily house-keeping jobs at home. But I couldn't stop looking at it. I touched it and squeezed it, and even measured it, trying to convince myself that it was getting smaller and that it would eventually go away.*

Diane

*I began to wonder whether I might have been endangering myself by delaying going to see my doctor for an examination. And I started to do all this head-work about whether I was actually being weak and afraid to face the reality that I might really have breast cancer, or about whether I was behaving as any reasonable woman would. I then began to wonder about whether I was being responsible, to myself, and to my family. I started to feel guilty, and especially so that if anything serious happened I would be blamed for hesitating.*

Linda

'Delay' has been investigated in relation to many disease types, but arguably the largest amount of enquiry is in the field of cancer (Macleod et al., 2009; Bish, et al., 2005). 'Patient delay' is a medical discourse which in oncological terms is generally described as when a patient fails to see a doctor despite suspicious symptoms or clear evidence of cancer (Andersen et al., 2009). Pack and Gallo (1938) first introduced the concept in 1938, seeing it as the interval between the onset of symptoms and the first visit to a physician.

Diane and Linda's delays in seeking medical consultations were constructed in similar ways, but for gendered as well as medical reasons. Both Diane and Linda found themselves positioned in a rigid structure of isolation, fear and invisibilising as a result of their emotional responses to the discovery of their breast symptoms. This was what Klawiter (2008) called "the architect of the closet" (p. 244), where the interplay of the medical, public health and gender discourses combined to engineer a place for them of confinement and secrecy. Diane pinned her hopes on the lump being something benign, caused as the result of a minor accident suffered at home. She was hampered emotionally by her belief that she would not be strong enough mentally to face what might be ahead of her. She described her reaction as mental "head-work" which was confrontational and draining. Diane blamed her gendered and socially-constructed labouring role as home-keeper, wife and mother as the cause of the lump ... then she re-felt, measured, convinced and deferred.

Linda also paused and did not divulge the existence of the lump while she considered the safety of her own well-being and that of her family. By considering her family first, she was taking up a moral position – that of the 'good' wife and mother. In doing so she had had to make a choice of action or inaction. The discursive practice of taking action is a clear example Foucault's notion of 'responsibilisation' (Osborne, 1997). This governmental strategy entailed an expectation that Diane and Linda would see the social risk of possible illness not as the responsibility of the state, but as lying in the domain for which they themselves were responsible, and to accept and act on it as a problem of 'self-care' (Lemke, 2001). The discursive practice of not immediately seeking meaning of the lump was an act of gendered responsibilisation, which ran counter to the notion of those 'responsible' women who quickly sought a diagnosis. But there was a poignancy about the discursive construct of these women in the solitariness of their actions at a time when they were so fearful, and in finding themselves positioned, indeed, in a discursively constructed 'closet' (Klawiter, 2008).

### **The Women Who Acted**

In contrast to the women who delayed in seeking medical help, or who engaged in behaviours of concealment, most of the women participants were galvanised into instant action on the discovery of a lump in their breast. These women, like those who delayed, experienced feelings of fear and anxiety, but these feelings served instead as an impetus for taking action. A diagnosis was sought in order to gain a fuller meaning of their health status. Eckermann (1997), in her analyses of gendered subjectivities, described

such discursive practices by women in this situation as practices of self-control - a form of Foucault's (1982b) technologies of self. The practice of self-control in seeking certainty about the significance of the lump was a mechanism by which some of the women sought to protect their role within the family, with their partner, and in work obligations.

*I felt that if I didn't see a doctor ASAP I was putting my whole self and family in jeopardy. I was very frightened, but the only sensible thing was to go and find out. One has to have such respect for this disease. If it strikes you, you should deal with it quickly. You have to put yourself and your family first.*

Rose

Rose is motivated by fear and by her maternal instinct (itself a common discursive construction) to protect her family, by deciding to immediately talk with her doctor. She saw it as her responsibility as a mother, and as the one with knowledge of her own body to face the threat of a serious, possibly life-threatening illness head-on, and to "deal with it" by seeking confirmation so that she could then inform her family. For Rose, there was to be no concealment, no secrets, no delay. Her comments revealed her determination to be certain about the significance of the lump, and her behaviour was one of urgency. She negotiated with herself between the fear and her sensible side - afraid, but able to overcome. She was very aware that it might be cancer, was respectful of it as a serious disease, but hoped that it would not be. She took what medicine and society construct as safe and sensible action. While certainty was threatening, certainty for Rose was also confirmation and meaningful. The subjectivity of the responsible citizen was to deal with the threat quickly and sensibly.

Such urgency, as depicted in the above quote, had a survival value as the women made moves to seek specialist help. By volunteering to come under the medical gaze, Rose hoped to quickly alleviate the threats to her body, home and family. She was the rational self, defender of her critical social role (Foucault, 1978; Duschinsky & Rocha, 2012). Psycho-social studies such as Zola (1966, 1973) and Radley (1989, 1994) have illustrated that bodily experience and the discovery of symptoms cannot be separated from elements such as cultural knowledge of disease and illness, social relations and social positioning within a family. As such, symptoms are confirmed in a 'social arena', governed as Foucault (1991) would say, by cultural socialisation and positioning (Hay, 2008). How this is done depends partly on the individual's position within that family or close social group, and there are specific gender influences on the symptom

interpretation process. For example, it has been hypothesised that sex and gender-specific socialisation results in differences in bodily awareness, (for women, such as menstruation, pregnancy, and labour pains). Hence, women are said to have a higher body awareness than men, which influences how they interpret physical symptoms such as in the breast (Andersen, et al., 2009). Also, some studies (Gannik, 1995) have indicated that the traditional female role encompasses more social responsibility in relation to the family than the male role. Rose, as a 'responsible mother', took action.

Foucauldian feminist writers (Weedon, 1987; Butler, 1990) have explored the complex relationships that exist between power, ideology, language and discourse. It is suggested in this research, that gender is a property, not of persons themselves, but of the *behaviours* to which members of a society ascribe a gendered meaning. Being a man or a woman involves appropriating gendered behaviours which are presented to others as his or her 'natural' way of behaving. This post-structural approach seeks to integrate individual experience and social power in a theory of subjectivity. Weedon (1987) defined subjectivity as the "conscious and unconscious thoughts and emotions of the individual, her sense of herself, and her ways of understanding her relation to the world" (p. 32). We see this in the ways that some of the women in this study, (and women in society at large), expected a mother to behave when she or her family were threatened. Rose, with a breast lump discovered, was characterised in terms of her own potential liability and also by her willingness to protect others from worry about her. Gender and medical discourses construct a desirable position of subjectivity for women to be alive, productive, loving, nurturing, and when ill, not to be a burden to others. Very evident in the deconstruction of Rose's account was the impact of the dominance of the medical discourse in the immediacy with which she sought to have the lump in her breast confirmed specifically by a medical practitioner, rather than by some other consultant. While fearful, she was urged into social compliance by the medicalisation of everyday life (Conrad, 1992; Riessman, 1992).

### **Gendered Techniques of Power in Discovery**

According to Giddens (1991), the individual in today's society experiences considerable generalised feelings of stress. Former constraints over choice have been significantly weakened, with the result that the individual is now confronted with a complex diversity of alternatives of action, especially in relation to life-style and matters of illness and health. Giddens viewed trust in others, for example trust in the expertise and manner of health professionals, as necessary if the individual is to avoid crippling anxieties. As



Lupton (1997) pointed out in her study of patient-doctor interactions, engagements with experts involve complex negotiations of power at the interpersonal level – often entailing emotional elements which can result in irrational outcomes.

Some of the women talked about interpersonal difficulties with their *male* GP as an inhibiting factor in seeking help on the discovery of a lump.

*I always seemed to be in that man's surgery about one thing or another, and so I thought I just couldn't go again about something which would probably turn out to be nothing. I didn't want to make a lot of fuss about nothing. On certain occasions in the past I had been made to feel by my GP that he thought I was a bit of a hypochondriac. He'd not said it directly of course, but he had said things like that I was complex or that my visits to his surgery kept his practice going.*

Jan

*It upset me when I heard about a male GP who didn't take a woman's concern about breast symptoms seriously. We women have to put our faith in doctors.*

Jan

Jan's first comment reflected the imbalance in the power relationship she felt between her and her male GP, to whom she refers as "that man". There are sexed and gendered complexities of the female body and the many physical changes a woman experiences in the course of her life-time – menarche, menstruation, pregnancy, menopause. Jan illustrated some of the women's experiences, that the reading of their own bodies was sometimes dismissed by health professionals. In combination, her comments also revealed a resonance of the gender and patriarchal discourses of the hysterical woman (Gilman et al., 1993; Smith-Rosenberg, 1972, 1985; Ussher, 2011). This experience surfaced in some of the women's accounts of being made to feel that their doctors considered them to be over-anxious and agitated. There was an intersection between the constructions of the anxious woman and the hysterical woman which emerged in some of the health professionals' accounts which I explore more fully in Chapter Seven.

As described in the reviews of the medical and gender discursive constructions of breast cancer, and illustrated earlier in this chapter, the female body has been constructed as 'ultimately untrustworthy' (Spitzack, 1987), risky and not to be relied on; bringing for women the identity and subjectivity of 'the risky self' (Nettleton, 1997; Ogden, 1995). Some of the women in the study talked about their experiences of doubting their own

truths about their bodies, and of therefore having to hold male health professionals in a strong position of trust to interpret their biological and medical symptoms in ways they could not do for themselves. For Jan it was all about what was said to the woman to whom she referred, the manner in which she was spoken to, and how it was interpreted. What some of the health professionals said and how they expressed themselves was interpreted in gendered terms by the women participants, and as voiced by Jan, carefully committed to memory.

Further, gender techniques of power were seen in the women's relationships with their own social bodies, and constructions of their individualised risky female body. Their breasts were perceived positively by most of the women as physical and emotional symbols of their own femininity, desirability, sexual pleasure, comfort, nurturing, maturity and beauty (Ryan & Jethá, 2010). However, when related to the threat of breast cancer, some of them constructed their breasts as troublesome, unreliable or failing.

*I actually wasn't that surprised when my doctor found the lump. I've always been embarrassed about my boobs. That's just it ... I see them as "boobs" or "mistakes". I had huge difficulties breast-feeding my babies, so I wasn't that surprised to think that there might have been another difficulty lurking about relating to them.*

Susan

Susan's comments reflected the power of the gender discourse of the risky female, and of the medicalisation of the female body. Her breasts had been a source of trouble to her in the past. Her breasts - those substantially sexually-constructed female organs - had earlier proved problematic in their inability to perform the expected natural and maternal function of feeding her babies. As a result, Susan held an underlying expectation that problems with her breasts were "lurking", and that they would continue to be problematic. Susan's excerpt showed the influence of previously experienced gender technologies of power on the difficulties some of the women had in their relationships with their bodies and/or their breasts in particularly gendered ways.

## **Summary**

In this chapter I have analysed the excerpts taken from the interviews of the women and health professionals with a specific focus on the first stage of the breast cancer experience – the discovery of symptoms. The ways in which the women's symptoms were discovered, and the different speaking positions of the women, their partners and

health professionals were described. In the analysis a distinction was made in the discursive construction or terminology between a generalised pre-diagnosed symptom and a medically-constructed sign after a confirmed diagnosis was made.

The analysis identified two dominant discourses by which the women and the health professionals constructed the discovery of breast symptoms - the medical discourse, and the gendered discourse. Most predominantly it was the medical discourse which constructed the discursive object of a lump, and which related a lump so closely to the medically-constructed disease of breast cancer as life-threatening for the women. The excerpts also showed the influence of a breast-specific public health discourse which significantly extended the medical discourse to this particular population of women, constructed as so very medically at risk (Foucault, 1991; Lupton, 1993). It was the medical and public health discourses that constructed cancer as a lethal disease. The only way for the women to gain certainty of truth was to submit to diagnostic and treatment processes which were likely to make them disfigured and unwell.

The subjectivity of being medically at risk by the discovery of a lump in the breast created considerable anxiety in all of the women, who then acted in one of two ways. Some of the women were galvanised into seeking a medical consultation immediately in order to make precise meaning of the lump, and thus the status of their health. The proximal and immediate discursive practices of conducting breast self-examinations, seeking a medical consultation (rather than some other type of meaning-making process), and submitting to GP examinations and mammography were laid down for these women in the medical and public health discourses as those of the responsible woman or citizen. However, the women's accounts also revealed the powerful influence of the, albeit more distal and indirect but never-the-less all-encompassing, neo-liberalist technique of power of responsabilisation

Other women delayed in seeking a diagnosis, or did not immediately divulge the existence of the lump or knowledge of it from their significant others. Despite knowing themselves to be at risk, this inaction was again deconstructed as the result of the fear generated by the medical and public health discourses about a lump in the breast. The techniques of power of medical surveillance generated such fear in these women that they initially took no action. All of the women in this study were aware of the significance of the lump, but the reasons for their delay in seeking medical advice delay

lay predominantly in being so fearful that what was considered by medicine to be common-sense did not prevail, and responsible actions were not taken.

The discourse of gender constructed the experience of the discovery of symptoms differently, but with similar emotional effects. The sexed discursive object was the female. Her gendered subject position was that of woman in 21<sup>st</sup> century New Zealand society, with ascribed female identity and roles. Within the gender discourse, breast lump-finding activities were what the responsible women did, because it was the gendered techniques of power which resulted in the women engaging in such self-surveillance practices.

On the discovery of symptoms, the woman assumed the subjectivity of the 'risky female'. Gendered discourse constructed her body as problematic, putting her role as mother and/or sexual partner at risk. Again, the women either immediately sought a medical consultation or delayed doing so, but their behaviour was specifically related to the protection from anxiety of family, partner, or work from the possible threat of breast cancer. The very thought of possibly having breast cancer, awoke fear in all of the women and their family members, friends and associates. This fear, constructed at the intersection of the medical and gender discourses, arose from the threat constituted by the disease of breast cancer to the woman's life, her integrity, her notions of invulnerability, and her identity as a woman. Feelings of helplessness and powerlessness were associated with fears of possibly being separated from what one held dear – one's husband, partner, lover, children, family and friends, work – and of losing a precious and symbolic body part. The significance of the breast both aesthetically and sensually to the woman's experience of herself as a woman and to her identity, was also therefore, a significant factor in the women's concealment of breast symptoms. Delay was a challenging problem because of the complexity of the roles that the medicine, public health and gender discourses played in the women's constructions of risk and in their help-seeking behaviours.

The general finding in this chapter, I argue, was that the interplay of the medical and gendered discourses produced considerable feelings of unease for both the women and the health professionals when the breast symptoms were first discovered. That is, the discovery of the medically-constructed phenomenon of a lump in the breast, by which ever means of surveillance, produced the discursive subjectivities and practices of the fearful woman and the anxious health professional.

In the next chapter I identify and analyse the dominant discourses which constructed the *diagnostic* process of the breast cancer experience, and the subject positions, subjectivities and discursive practices which arose for both the women and the health professionals as a result of the technologies of power inherent in these discourses.

## CHAPTER SEVEN: THE DISCURSIVE FIELD OF DIAGNOSIS

### Introduction

In this chapter I present my identification and analysis of the dominant discourses which were strongly indicated in the women's experiences of moving into the medical system and receiving a confirmed medical *diagnosis* of breast cancer. As a result of their diagnostic needs, the women interacted with a variety of health professionals and specialists, all of whom had different ascribed roles and practices. I also present my exploration of the discourses deployed by the health professionals who were involved in a diagnostic process with women, and in particular the imparting of a confirmed diagnosis.

My analysis showed that there were two dominant discourses which constructed the diagnostic experience – the medical discourse and the gender discourse. These were the same two discourses that emerged in the discovery of symptoms stage, described in Chapter Six. I argue that these discourses, separately and in combination, again produced significant emotional reactions in both the women and the health professionals and impacted on the doctor-patient relationship.

### The Medical Discourse of Diagnosis

The word 'diagnosis' is derived from two Greek words meaning 'apart' and 'to perceive', and is used most often in medicine and related medical fields. Such definitions immediately draw attention to a conceptualisation or construction that something is discerned or distinguished as different, and imply the classification of separate states and distinct categories. Within medicine, the process of making a diagnosis is central to subsequent constructions of disease and illness by which medical professionals determine the existence and legitimacy of a medical condition (Foucault, 1978; Rose, 1994). The diagnostic process is a process of medical surveillance, and being so integral to the theory and practice of medicine, is a deeply embedded practice of the medical discourse.

The medical discourse is seen by some writers as constructing diagnosis in two major ways – process and category (Blaxter, 1978; Brown, 1995). Process is the set of interactions which leads to the definition of the category (and to its imposition in particular cases), and category is the classification of disease and the location of where

the diagnosis fits within medical knowledge. Medicine has reified definitions of disease into which professionals and others fit their observations and empirical testing. Medical diagnosis thus has various functions. For the person seeking medical meaning of symptoms, a confirmed diagnosis provides an individualised and personalised way of knowing what is wrong. For health practitioners, the professional mastering of knowledge of the problem provides a high level of control at the individual care level. In addition, diagnosis frequently determines the course of treatment, although treatment is often determined by many other factors. For both the person and the professional, diagnosis also leads to a probable prognosis – a forecast of life, so that all in all, the giving and receiving of a diagnosis can be an emotionally challenging experience for the involved parties (Brown, 1995; Hay, 2008).

### **The Medical Discursive Object – The Cancerous Tumour**

In Chapter Six I discussed the difference between the pre-diagnosed, subjectively-felt ‘symptom’ and the medically-constructed ‘sign’. When a symptom is confirmed by medical diagnosis as a cause or result of illness or disease, it is termed by a medical reader of the body such as an oncologist, as a sign. The symptom is re-constructed by medical discourse as a sign.

*I read mammography plates all day. I see deep and light shadows on these plates, and their configuration, depth, shape and size enable me to discern possible cancerous tumours from the benign. Women come in talking about finding a lump. Pathological cellular biopsy confirms a cancerous tumour.*

Geoff, Oncologist

Geoff was verbalising the practice of medical semiotics - the science of how medical symptoms and signs are produced, shared and interpreted by oncologists like him (Burnum, 1993; Malterud, 1999). It is the process undertaken by medical diagnosticians which involves the making of a connection between a primary symptom (visible by human eye or technology or palpable, such as a breast lump, dimpling of breast skin, or discharge from the nipple) to a confirmed diagnosis of the disease of breast cancer. This is an example of Foucault’s (1973) concept of the medical ‘gaze’ presented in *The Birth of the Clinic* – the defining of the body by the medical and scientific community.

Geoff demonstrated application of Foucault’s (1972) grids of specification by which cell types were classified as abnormal from normal, and a lump diagnosed as a cancerous tumour. The tumour was constructed by Geoff as “an object of interest for the

medical gaze” (Zita, 1988, p. 90). His re-construction of the woman’s subjective ‘lump’ to a cancerous tumour through the use of medical technology (surveillance by machines), removed the lump from the social context in which it had been discovered, and problematised it as a clinically detectable organic event (Zita, 1988). Medical discourse thus provided objective and scientific legitimation for the re-definition of a part of a woman’s body which it constructed as problematic and dangerous (Harding, 1997). Despite his specialist status however, Geoff’s comment reflected his dependency on medical technology to confirm or disconfirm breast cancer.

### **The Subject Position of the Woman Seeking a Medical Diagnosis**

The discovery of symptoms is the *raison d’être* for a medical consultation, and is dependent on it to achieve definition. All of the women in this study visited their doctors with unspecified symptoms. They all knew the possible meaning of those symptoms, but within the medical discourse even their sensory or kinetic sense of the lump was not regarded as valid, and thus their subject position of the knower of their own bodies was not considered valid either. The speaker of ‘the truth’ was the medical professional, and after a diagnostic process the women returned home with the named disease, breast cancer. The doctor-patient relationship has long been regarded as the critical interactive encounter in the diagnosis and treatment of illness (Gwyn, 2002). The doctor’s role is seen as crucial in Western culture because the figure of the doctor is invested with considerable importance and power. In this study, the doctor-patient relationship was pivotal in many of the women’s accounts of their experience of diagnosis. Such encounters in some cases redefined the boundaries of this relationship.

*My doctor of 20 years did not, or rather could not make eye contact with me as he passed through the waiting room where I sat waiting for my appointment with him to tell me the results of the biopsy. He had always been jovial and welcoming, an arm out to guide me into his room. His lack of eye contact told me that he was afraid of telling me something. This seemed ironic because he had such a good name with other medical people as being forthright but considerate.*

Rose

Rose’s experience showed that the extraction of meaning from the information or message conveyed during face-to-face communication was based for her on several factors, including the words of the message, the tone of voice, and body language. The



processes involved for both her and her doctor were very dependent on the quality and type of reaction and communication between the two. Women like Rose and the GP participants in this study, all identified the period following discovery of symptoms and before the definitive diagnosis as very stressful for them, and potentially stress-provoking for the health professional. The women continued with their emotional responses to the symptoms and were further challenged by thoughts of diagnosis and the need to undergo treatment, all in a relatively short period of time.

All of the women, in presenting themselves for a medical consultation, were embarking on a diagnostic process which by necessity forced them to interact with unfamiliar specialists and terminology, and with complex technology and technological practices. In seeking a diagnosis, they were positioned within the medical discourse in relationship to the tumour. They sought meaning of the lump, a definition of what it meant, and for this they had to turn to the medical profession.

*I had no choice. I had to get a diagnosis. I had to know one way or the other. So I went through the whole diagnosis thing – mammography, ultrasound, needle biopsy. This involved three consultations with strange people in strange places. I have always been shy about showing my body, and I was really embarrassed at having to bare my breast in front of unfamiliar specialist and technicians and nurses. So I told myself to just be brave, but I certainly felt exposed and observed.*

Carol

Carol did not conceal her symptoms and did not delay in seeking a medical consultation. By her actions she assumed the subjectivity of the ‘docile body’ (Foucault, 1973) because she had little option but to passively allow the diagnostic process to be conducted over and within her body. Carol’s situation revealed how the medical discourse shut down the possibilities of cancer being spoken about in ways other than medical (Foucault, 1973).

*But it was no longer my body. Having some-one else stretch my body and breasts across the mammography machine in all sorts of contortions, and stand with no breath for what seems ages, put me in a position which was unnatural and uncomfortable mentally and physically. Just getting a diagnosis definitely moved me out of my comfort zone. I endured the mammography, being*

*squashed more and more painfully. They took many more images than usual.  
My nostrils flared because I could smell trouble in the wind.*

Pam

The process of seeking meaning of the tumour, caused Pam to feel that her body was no longer her own, or rather, that a part of her body was now possessed by others. She talked about her body and breast being emotionally and subjectively experienced by her in ways that some-one else physically manipulated and objectively measured. Her body, her breast was elsewhere, reinforcing medicine's diagnostic process of separating the breast from its natural social and ideological context (Harding, 1997). Pam sensed a slipping away of her position and identity as a healthy woman to something else.

Carol and Pam's submitting to the discursive practice of the diagnostic process, placed them further on the curved trajectory of discovery, diagnosis, treatment and recovery – a pathway pre-defined by medical discourse. Being in such a position, emphasised their reliance on, and need to trust the medical profession to diagnose with accuracy. They were now firmly positioned in the 'gaze' of breast surgeons and oncologists. Carol actually stated that she had "no choice" but to turn to medical specialists who had the knowledge and power to know the body and to conduct expert readings of it. Armstrong (1994) provided a classic Foucauldian description of the person at the end of the stethoscope, or in the gaze of the expert. Every time the 'stethoscope' is applied to a woman by an expert, it reinforces the fact that she possesses an analysable body with discrete organs and tissues which might harbour a pathological lesion, and which requires the expertise of the specialist to diagnose.

Carol and Pam revealed the emotional distress they experience in the examination process, particularly in having to expose their breasts in less intimate settings than usual. In general, women who undergo regular mammography comment on the physical discomfort and embarrassment of this screening procedure (Miller, et al., 2009), but accept it as that which must be endured. Some of the study participants talked further about finding themselves in a disempowering position by the very nature of the environment and atmosphere of the examinations and examining rooms of the clinical diagnostic setting. The rooms were very large or too small, cold, metallic and technical. The machinery made Carol and Pam feel exposed, anxious and afraid by having to submit to the formidable science and practices of oncology.

The circumstances in which the diagnosis was imparted impacted greatly on some of the women, and contributed further to their feelings of distress.

*I received a phone message to make an appointment with a specialist. That was the flat way I learnt I had breast cancer. No personal words, no reassurances, no clarifications, just a number to ring. Immediately my suspicions became a reality, and I knew the threat I faced.*

Mimi

*There was a female imaging-person present at my needle biopsy, undoubtedly well qualified in the technical side of her job. She seemed to have it all off pat. She told me that it was probably just a cyst and I'd have nothing to worry about. But after telling me that it wasn't a cyst, and so by assumption I guessed it was a tumour, she just said "Good luck". I knew even then that I had breast cancer. The consultation later was short, sharp and not so sweet. "You've got breast cancer", he said. "I knew that", I said to him "when you couldn't look me in the eye.*

Nancy

The behaviour of the health professional, and the mere phone call were equally unnerving experiences for Mimi and Nancy. As Foucault (1980) argued, we are subjects, but we are also subjected to discursive practices, in this case distinctly unsettling. Mimi and Nancy showed that the influential effect of how language is used, whether over the phone or face-to-face in the medical encounter, should not be underestimated. Given that Nancy was being investigated for breast cancer, the technician's salutation of good wishes, albeit intended as supportive, and the consultant's lack of eye contact, led to her self-identification as a 'breast cancer patient' even before this had been medically confirmed.

### **The Subject Position of the Consultant Health Professional**

The group of people on whom these women breast cancer had to depend, were highly trained experts – specialists in the field of oncology. A common way of their describing such a consultation was "seeing a specialist". The very role of 'specialist' was constructed as one who was a professional, a dedicated, high-quality individual with authority. This placed the diagnostician in a powerful place within the woman-professional relationship.

*There is something very satisfying about being able to give a patient a diagnosis. Obviously it is much better if the results are negative, but the capacity of medicine to scientifically confirm or disconfirm suspicions pleases me. I'm proud of our ability to be able to do that.*

Geoff, Oncologist

Diagnosis is central to the work of medicine, and differential diagnosis is probably the most rewarding and rewarded skill for medical specialists (Holland & Weiss, 2010), as evidenced in Geoff's satisfaction. The diagnostician's challenge is to understand and interpret scientific information, and to impart the diagnosis. GPs are often confronted with 'unorganised illness' (Fox, 1997), an agglomeration of person-reported symptoms which may be unclear and seemingly unconnected. It is the medical discourse that identifies these symptoms as unclear and has the knowledge base to make connections and confirm the signs of a medical diagnosis.

The power accorded to the diagnosing specialist can be seen in medicine's giving itself permission to change the terminology of the pre-diagnosed breast 'lump'. As described earlier, while symptoms are problems that a person notices or feels and chooses to reveal, report or ignore, signs are what Geoff the oncologist could objectively detect, measure and technologically assess. Obviously medicine objectively sees, rather than subjectively experiences, and detects rather than discovers. Certainly much medical work consists of routine diagnoses of problems, many of which are straightforward. However, the diagnostic consultation process was complicated and rendered stressful for some of the health professionals and women in this study, in their respective roles as the imparter and the receiver of a confirmed diagnosis of breast cancer. I analyse the emotional impact of these subject positions in the following sections.

### **The Subjectivity of the Woman Diagnosed with Breast Cancer: 'She' Becomes a 'Patient'**

All of the women in this study were examined first by their GP and then referred for mammography. After mammography, most were called back to their GP's surgery, and some to a hospital or to a breast clinic, to be informed of the diagnostic results. A medical diagnosis is seldom solely a biological fact, but rather the outcome of a process where biological, cultural and social elements are interwoven (Brown, 1995; Burnum, 1993; Holland, 1998). As on the discovering of symptoms, the news that she had breast cancer came as a great shock to all of the women, and was usually broken in one short sentence of the sort... "You have breast cancer". The previously healthy women in this

study were thus *suddenly* re-constructed by medical discourse as ‘unhealthy’, ‘ill’, ‘sick’ or ‘diseased’ (Brown, 1995; Burnum, 1993; Hay, 2008).

*I was a person and then I became a Patient with a capital P. I felt as if I had been re-classified into some other abnormal group. With all that was ahead of me, I felt as if I had a new identity. I had been moved from just being checked out physically to becoming ‘a case’, a statistic. And I struggled with over-hearing myself referred to as a cancer patient. I was frightened by that label.*

Carol

Some women talk in the media about the intrinsic ‘whirl-wind of emotions’ in this life-changing event, for their lives, as they knew them up to this point, would be drastically altered, at least for the foreseeable future. Carol was now constructed and identified by the medical profession as ‘a patient’, but she struggled to identify herself in this way. She was forced to face an enormous new fact about herself – that she had cancer. The confirmed diagnosis changed her status to that of patient. This meant that she was now on the medical trajectory and fell within the boundaries of medical treatment and care. Most of the women in the study felt that their current lives were under threat in their facing of treatment. They found themselves in an extraordinary position which, for most, was unlike anything they had experienced previously (other than some surgeries or childbirth).

Turner (1996) reminded us that as human beings we are bodies and have bodies. But as he pointed out, even though we have bodies, at times we do not necessarily have ownership or control over our identity or our well-being. Carol revealed a significant degree of bodily confusion and uncertainty; her body had been re-constructed and re-classified by medical diagnosis and discourse. Her comment reinforced that when it came to making sense of her abnormal bodily symptom, it was predominantly medicine which controlled the means of the production of outside expert knowledge about that symptom, in order to confirm it as a medical sign. Medical discourse constructed Carol’s singular female body on the basis of common, normal physiological processes and less common, abnormal processes (Turner, 1996). Medical discourse also constructed her position as belonging to a homogenous group of patients, with common symptom narratives and common needs for clinical intervention. For Carol it felt as if she had been placed in some ‘abnormal group’. Her description of moving from ‘person’ to ‘Patient’ was illustrative of the women’s transitioning into a new identity, which stimulated an array of thoughts and emotions. Carol’s excerpt revealed the

subject positioning of her docility, or her little choice, in that she was being moved by the medical system to a new status, rather than moving herself.

The predominant outcome for most of the women then, as exemplified in Carol's experience, was their identification as a 'patient' – becoming a case, a statistic. The diagnosis, even the physical diagnostic examination, involved documentary techniques which named and branded Carol as something and someone very different to who and what she was only minutes before – healthy woman to diseased patient. 'She' became 'a patient' because her breast was not normal. Her current condition was measured against the medically-designated norm, and the features of each case kept by the medical system so that she could be described, judged, measured and compared with others (Foucault, 1991). The tumour now positioned Carol as deviant from the norm. Worse, she became discursively constructed as "a Patient with a capital P", signifying how seriously medicine viewed this status.

Carol's involuntary transition was analogous to Jewson's (1976) bio-political construction of the 'disappearance of the sick man' in his home and the emergence of 'the patient' in a hospital or some other clinical setting. In the world of breast cancer diagnosis by impersonal technological means, Carol was treated as an object, with an accompanied self-perceived loss of her essential individuality. It has been said (Holland & Weiss, 2010) that nowhere is the extreme of the bio-medical model more evident than in the diagnosis and treatment of cancer patients. This has been the result of the rapid evolution of technological intervention and the simultaneous decline in the more personalised care epitomised by the characterisation of 'the family GP'. Loss of the patient's perspective, and indeed the loss of the person of the patient, so aptly described by Carol's transition from person to Patient, has come to characterise high-technology medicine. As medical sociologist Arthur Frank (1991) noted "Ours is the first age in history where people can look inside themselves and see their vital organs working" - a "vision of inner space" (p.18). This is particularly pertinent to breast cancer with mammography, calcification biopsy and ultrasound thermo-graphic imaging. But Frank noted too, that such expertise can also depersonalise the person under the technological gaze. Upon being diagnosed, the women quickly became familiar with medical terms, applied them to themselves, and identified themselves in this way, as reflected in Carol's reference to her feeling of loss of her former identity. Such resultant subject positions were described by Frank (1991) as "a triumph of science and a lapse of humanity" (p. 27). Psycho-oncologists (Holland, 2010) argue that patients like Carol

should not be, but yet seem to be, very much characterised by a diagnostic label, an “onerous citizenship” of “that other place” (Sontag, 1978, p. 3). Receiving a confirmed diagnosis of breast cancer opened up in the women in this study a whole gamut of emotions associated with re-identification.

### **The Subjectivity of the Breaker of ‘Bad News’**

The describing of the imparting of a confirmed diagnosis of cancer as ‘bad news’ which must be ‘broken’ to the patient, was a dominant medical practice which emerged in the doctor-patient consultations cited in this study. It was considered ‘bad news’ by the doctors and women alike, because the women’s well-being and lives were threatened. ‘Bad news’ is a term used frequently in medical journals, and is synonymous with cancer (Fallowfield & Jenkins, 2004; Salander, 2002; Sweeny & Shepperd, 2009). In contrast to earlier times when doctors avoided giving a clear diagnosis or talked in euphemisms, most physicians in Western countries tell patients when their diagnosis is cancer, and most patients prefer to be told (Breaden, 2008; Galgut, 2010). However, the clinicians in this study found the bad news consultation to be an extremely difficult task (Fallowfield & Jenkins, 2004; Moscrop, 2011).

Most of the health professionals interviewed for this study, spoke of their emotional involvement in the process of imparting a confirmed diagnosis of breast cancer, and of the stress this caused them. All of them talked not only about the difficulty in breaking the bad news, but also about the extent to which the bad news consultation could be affected by the perceived quality of the relationship between them and their patients (Walker et al., 1990).

*We doctors have what we call ‘heart-dropping consultations’. That’s when you see the patient’s name on the list of up-coming appointments, and you dread what you are going to have to tell her.*

Tony, GP

*Breaking the bad news almost always, and not unexpectedly, has upsetting effects for both the giver and the receiver. The definite answer is always a shock - some women describe it as a crisis. Receiving a diagnosis of breast cancer unleashes the great unknown, coupled rightly so with something that is terrifying.*

Alasdair, Oncologist

Tony and Alasdair showed the expectation that a confirmed diagnosis of cancer would be disturbing both for the receiver and for the professional who must convey it. The strength of Alasdair's belief in the medical system was seen however, in his construction of medical truth as "the definite answer" - and that definite knowledge was the construction of breast cancer as a life-threatening disease. Even so, the giving of such information was indeed very distressing for the professionals in this study. Alasdair's comments and Geoff's, quoted at the beginning of this chapter and again below, stated that it is the pathological or cellular biopsy that confirmed a cancerous tumour. Medical discourse turned suspicion into fact, a reality which must be dealt with in a particular way. The bad news was imparted by professionals, the only people endowed and sanctioned by society to have the knowledge to do so, but the role of imparter brought with it certain emotional challenges.

**The Discursive Practices of the Breaker of Bad News. Medicine's Dilemma: Breast-centred or Patient-centred?**

On the surface, the actions of the professionals in the position of confirming a diagnosis were to perform and interpret biopsies and/or to then inform the patient of this medical fact. The imparting of information which threatened, at best, a woman's well-being, and at worst, her life, held considerable responsibility and expectations for the behaviour of the professional (Salander, 2002). The language used was in itself a discursive practice which, I believe, had significant effects for both the speaker and those spoken to. In the first instance, the language used by the professionals as information-givers and diagnosis imparters, had the potential to create subject positions and subjectivities for them which were read by some of the women as distant and untouchable. Some of the health professionals were unable to engage in the patient-as-person relationship to the extent that would have been more desirable from the point of view of both parties (Mead & Bower, 2000; Miller, 2010).

*My only concern is that every patient on presentation should be assessed for potential curability. It is convenient to take away bits of breast and codify these using the clinical TNM system, which classifies tumours by size and the presence or absence of metastases. This makes it easier for me to convey to the patient.*

Geoff, Oncologist

*As the person giving the diagnosis, I believe it is my responsibility to give information about the probability of cure, disease stage, types of curative*



*treatment, and five and ten year survival figures. This puts me in a position of “playing God” or being some sort of oracle reader. This is an aloof place to be, detached even.*

Tony, GP

*In certain interpersonal situations connected with the diagnosis of breast cancer patients, I have been told by patients that some specialists are perceived by them as being more interested in the lump than in the woman herself. This, in my opinion, is irresponsible doctoring. We should not be distant; women in this position are so much more than just categories or statistical numbers.*

Rafi, Breast Surgeon

Obviously at the interview, Geoff was not talking to one of his patients, but he used particularly technological language, generally not well understood by the lay-person. The combination of subject position and subjectivity within the medical technique of power of Foucault's grids of specification was seen in both Geoff and Tony's categorisation of cancer in various ways, and this in turn allowed them to forecast the future in terms of probable curability. They were both steadfast in their belief in the notion of a possible cure. Geoff's expressed concern was about determining the curability of his patients, which he constructed as his ascribed societal role. Tony too, saw this as his responsibility, but constructed it metaphorically in the sense of the infallible authority of one who can predict the future. Geoff made the task easier for himself by using medical terminology. Tony and Rafi both recognised the effect distancing might have on patients. It might be argued, that the awareness and acknowledgement of the emotions of breast cancer patients at such a precarious time was a critical discursive practice expected by the women of their health practitioners. From a discourse analytic process, the women's reactions were read through a discursive lens and then interpreted as emotional. In the difficult circumstances of diagnosis, the mechanisation and dehumanising of breast cancer patients as shown in Rafi's description of others' practices reinforced the still-common medical practice that the responsible and rational physician may feel more emotionally secure in the position of objective observer rather than subjective supporter. In keeping with the post-structural notion of multiple truths, this was one way that the discursive strategy deployed by such physicians could be interpreted.

*He didn't comfort me at all. He just frightened me; it was as if I was dead already.*

Anne

*Does medical training teach doctors to be distant? Are they not taught to take feelings into consideration? Do they just believe that death is a failure?*

Rose

Anne and Rose's expectations of their professionals showed that the perceived subjectivity or objectivity of the doctor-patient relationship was disconcerting for some of the women. Some of their perceptions of their health professionals' discursive practices, when informing them of their condition, were described as "cold", "uninterested", or "distant". Acting responsibly was an ascribed role and expected practice of the professionals; however, at the point of telling a patient she had breast cancer, they were in the vexed position of how much information to give and at what stage to give it. This, in itself, was an anxiety-provoking situation for most of them. For example,

*It is a double-whammy though because this type of information-seeking and giving is also the most threatening to patients. Talk of surgery, radiation, chemotherapy, chances of survival is very threatening. It is hard to know how far to go with all of this in a consultation, because we don't get to see the patients that often. Often the next time is when they are going in for surgery.*

Michael, Breast Surgeon

*Breast cancer and diagnostic information are some of the types of information I find extremely difficult to give. That is the worst part of my job. Of course I present optimism when there is a chance of cure, but to try and be up-beat and positive when it is already obvious that things have gone too far, is inwardly chilling.*

Tony, GP

Michael found himself in a difficult position, because even the smallest amount of information he must impart would be constructed by his patient as ominous. There was also a hint of time pressure in what he said, so that he was burdened with the responsibility of gauging exactly how much information to give at this particular time and with this particular patient.

Tony also showed the stress incumbent on the professional in such an interaction, constructed by him as a most unpleasant task which he attempted to imbue with optimism, though only when there was the possibility of the woman surviving. He revealed the ethical practice of being the honest practitioner who told the 'truth' (as it was constructed within the medical discourse). The determination of the future of the woman was based, for Tony, on certain pathological evidence.

Michael and Tony's comments have been replicated in studies (Holland, 2010; Mead & Bower, 2000) which showed that at the point of imparting a diagnosis, there were two main types of information-seeking and giving: disease-orientated and action-orientated. These studies showed that disease-orientated information was about the disease, treatment, treatment types, side-effects and survival rates. From a health professional's perspective, this type of information was what cancer patients needed most, so that it was then possible for them to appraise their situation, and enact responses. This type of information was saturated with medical terminology, heavily invested in by specialists, surgeons and oncologists. The second type was action-orientated information about where a patient could access help for more practical solutions, and was most often provided by breast care nurses (V. Adams, 2007; Donnelly, 1995; Houldin et al., 1996; Lugton, 2002).

All of the health professionals in this study, like their patients, constructed breast cancer as life-threatening, and its processes of diagnosis and treatment, fear-provoking. Also like their patients, some employed defensive rationalisations when trying to assuage their patients' and their own worries. In studies of doctors' tactics of avoidance or delay, (Andersen et al., 2009; Bish et al., 2005; Meechan et al., 2003) discursive rationalisations were most often reported to have occurred. People in modern society, including medical professionals, expected a cure and resolution. When a cure was not likely, feelings of helplessness could challenge the physician.

A critical element in the imparting of a confirmed diagnosis of breast cancer in my study was then, the positivity, or otherwise, of the interaction between the informer and the receiver. Psycho-oncological research (Holland, 2010) has emphasised that patients can tolerate bad news with less negative emotion when they perceive their health professional to be experienced, humane, and available for explanation and comfort.

*I'm relieved when my patients understand straightaway what I'm saying ...  
that they get that they have breast cancer, and have some understanding of*

*what will happen next. Long explanations about treatments, diagrams, and the inevitable questions about outcomes are time-consuming and stressful. “Switched-on” patients are the best.*

Charles, Breast Surgeon

*From my point of view, such difficult consultations are always a type of “interpersonal event”. I am careful not to show anxiety in my voice. I try to show understanding through insightfulness and empathy, not pity. I always try to be aware of my own feelings, and to control them with regard to the patients and what they are telling me, and what I have to tell them. I believe that this helps them to have confidence and trust in me and the treatment options.*

Michael, Breast Surgeon

*Breast cancer is such a dastardly thing. I always touch my patient in some way, a touch or squeeze of the hand, or a hug if I know her well, after I’ve said something like “Are you prepared to face the fact that you might have to have a breast removed?”*

Tony, GP

In contrast to Charles, Michael and Tony characterised the health professional who constructed the medical consultation as a person-to-person relationship wherein the professional could experience and express empathy with their patient. They showed understanding of the emotional state of their patients, whom they identified as emotionally stressed and in need of a caring approach. ‘Holding hands’, either literally or figuratively, is an established concept in medical care (Tuckett, 1999), and one practised by Michael and Tony without fear of any loss of their authoritative status. As practitioners, Michael and Tony were illustrative of the recent shift of medical gaze to the, some would say, more humanising approaches of psycho-social medicine (Holland, 2010). This gaze offers (breast) cancer patients freedom through the telling of their experiences, thoughts and feelings - Foucault’s (1978) ‘confessing’. What underpins all of this with regard to breast cancer is the negative and undesirable construction of disfigurement (and death). The notion of disfigurement disturbs the sexed and gendered notion of the ideal female body with two breasts. It was the threat to this ideal which produced such responses by some of the women to their diagnosis.

The situation for the health professional giving a confirmed diagnosis was not an easy one, because it was not only their patients who felt fear and anxiety over the disease, stressful treatments to come, or about death. Some of the health professionals

experienced similar discomfort and anxiety (Salander, 2002), and like their women patients, they were positioned by these feelings in different ways. Diagnosis, patient shock, fear, anger, and grief, and a belief that the cancer must be dealt with quickly were identified as substantial stressors for some of them, but not the only ones. The era of medicine as business, consumerism and managed care have mandated shorter patient visits and an increasing amount of documentation, all of which, some of them commented, had diminished the time available for them to talk with their patients (Fins, 2007; Moloney & Paul, 1991).

*Decisions and management plans need to be made with some speed. Decisions can have serious consequences. Well, you know, sometimes I think that I just cleanly “manage” the disease medically and surgically.*

Raewyn, Breast Surgeon

Extraordinary professional expectations contributed to the stress burden Raewyn carried. The health professionals were not only expected to be scientifically expert providers, technologically competent and empathetic communicators, but also to be able to personally deal with the impact of their patients' physical and psychological distress. Other than a singular medical focus on the tumour, a seemingly detached style of engagement provided a measure of emotional protection for some of the professionals, as shown by Alasdair:

*Talking to a shocked person is relatively useless. Using comforting words or giving information does not alleviate some patients' distress at that time. Most women are in an acute state of shock and do not take in information well. Some turn just plain nasty. Sometimes a patient's aggression and the terror which lies behind it make me afraid. My unwillingness to interrupt patients' tirades is a sort of self-protection, I suppose; my kind of resistance to getting down to the difficult stuff which we should be attending to.*

Alasdair, Oncologist

Alasdair recognised that a confirmed diagnosis was upsetting for patients, and obviously had had first-hand experience of their considerable distress, which he perceived had sometimes been turned on him. He confessed to being fearful of such responses and to engaging in self-protective strategies, which he acknowledged as a form of resistance. The medical discourse gave him the position of bad news breaker, and this position left him feeling vulnerable to the women's responses. Two additional challenges for

Alasdair then, when communicating a confirmed diagnosis, were to manage both his patient's emotional response to the bad news, and to manage his own reactions to the patient's response. Imparting a diagnosis is not unlike the many other technical skills which comprise the basis of medical discursive practice and for which proficiency is demanded (Foucault, 1970). Nonetheless, those clinically technical skills belong to a domain which has traditionally been afforded scientific status, while issues arising from managing emotional reactions and communication belong to a domain which has not (Haas et al., 2005; Holland, 1998; Holland & Lewis, 2000).

As Foucault (1970) noted, incorporation of the patient's perspective into the medical system is not simple. Alasdair's fear reflected the dichotomy of the singularity of the bio-medical gaze and the patient-centred alternative which focusses on complex dimensions of functioning, behaviours and feelings (Wilson & Cleary, 1995). Alasdair was caught in the dilemma that "in practice [oncology] should ideally [be] a single and integrated approach in which the clinical reasoning process proceeds through both the diagnosis and dialogue concurrently" (Holland, 1998, p. 7). This reconstruction of the 'patient-as-person' included for Alasdair much more than just the diagnosis per se. Medicine now advocates a patient-centred approach and the 'triaxial diagnoses' of the three major areas of patients' potential problems inherent in receiving a diagnosis – the impact of the biological, psychological and social aspects of having breast cancer. "Those health professionals who do not perform these triaxial diagnoses well, can find themselves experiencing uncomfortable reactions from their patients" (Roter & Fallowfield, 1998, p. 1078).

### **The Discursive Practices of the Woman Diagnosed with Breast Cancer**

The process of being diagnosed with an illness or disease is in itself a discursive practice which aligns the speaker in relation to the discursive object of the cancerous tumour. The purposeful actions of all the women in this study, in seeking medical meaning of the tumour and an understanding of the implications for themselves and others, were illustrative of the Foucauldian concept of the responsible citizen's duty of care not only of the self, but also of care about the self, and of the care for others (Rose, 1999). The actions that a woman took were strongly influenced by the power of medicine's strategies of surveillance.

*I couldn't take the risk. Breast cancer seems to be very common. Information about it is in all the women's health magazines. The diagnosis settled my*

*doubts once and for all. But it also doused my hope and my family's that I would be OK; that it might be a false-alarm.*

Jo

An emphasis on the self-management of risk and self-care has become increasingly evident in health promotion strategies and cancer screening policies. Jo's comment exemplified the basic premise of neo-liberal rationality which requires women to adopt a calculative and prudent attitude with respect to the risks and dangers of breast cancer (American Cancer Society, 2013; New Zealand Cancer Society, 2014). Jo's pursuit of a risk-free existence, by receiving a diagnosis and undergoing treatment was constructed by the public health discourse as exercising self-control and self-care, thereby fulfilling her obligations as an autonomous, active and responsible citizen. Foucault's argument that the exercising of power is positive was seen in the empowerment Jo felt in her accessing medical technology, which would move her from her current position of symptom-obsessed. In undergoing diagnostic mammography or biopsy, she was a clear example of the positivity of Foucault's (1984) concept of bio-power, and of the breast clinic as an enabling site of bio-power. Generally described, bio-power is power over life. Jo knew what breast cancer meant and acted 'responsibly' by embarking on a diagnostic process. Even those women participants who initially delayed in seeking a diagnosis all finally did so. Foucault (1982a) argued that power is not something owned but rather a constructive element flowing through interactions, dealings and relationships. Jo exemplified the extent to which public health's technology of bio-power was a subtle, constant and ubiquitous influence over hers and all of the women participants' lives.

### **Medical and Public Health Techniques of Power in Diagnosis**

The imparting of a diagnosis is medically constructed as something that occurs firstly between the patient and the health professional providing medical care. One of the means by which diagnosis is realised is by naming the disease. In the classificatory constructions and discursive practices of the medical world, one can only be cured of something that has a name. The universally-accepted facility of science and medicine to name and diagnose biological differences is an unparalleled technique of power and control (Armstrong, 1983, 1994, 1995, 1997).

*The diagnosis was final. I finally knew what it was. It had a label. I had a label, and so I became part of the statistics. Statistics aside, I was terrified, but*

*I was grateful that modern medical science had a fairly straight-forward way of confirming it for me.*

Carol

Foucault's (1984) analysis of bio-power provided two axes through which power worked in relation to Carol's female body and breast cancer - one working on the individual body – 'anatomo-politics of the body', the other 'bio-politics of population' working through populations. His concept of 'anatomo-politics' was particularly apt at this point of Carol's breast cancer experience, because of its construction of her as 'docile'... sitting in a diagnostician's clinic receiving the confirmed diagnosis. Carol showed that as a breast cancer patient, she continued to be constructed by specialist medical discourse as a passive object, whose cancerous tumour contained interesting pathology. Modern analytic techniques of surveillance machinery objectively locate disease amongst the lesions of tissues, organs, and cells of the human body, and its language resonates with scientific terminology. The subject of Carol was the medicalised, docile body of the woman under the medical gaze – a passive body in the grip of powerful medical discourses and practices. She was the passive receiver of medical information and advice from oncological specialists, and the consumer of medical services which articulated the knowledge and ability to diagnose breast cancer accurately. But her comment also showed that she was constructed by medical discourse not only as a cancer patient, but also as "a resource and manageable object" (Hakosalo, 1991 p. 9). As Foucault (1991) said, a docile body is one that can be "subjected, used, transformed, and improved" (p. 136) because of its inability to return the clinical gaze.

Medical discourse had placed Carol's symptoms on a diagnostic grid of specification (Foucault, 1972), and it was by those statistics that she now identified herself. This positioning also indicated the extent to which bio-politics employs regulatory controls and interventions to manage a population (Foucault, 1984). Carol, as an individual woman being tested by "bits of breast" (Geoff, Oncologist), was representative of an entire population of women at risk of developing breast cancer. Because of society's awareness of the size of the breast cancer 'problem', described by many in the Western world as of 'epidemic' proportions (Kasper & Ferguson, 2000; Lantz & Booth, 1998; Mukherjea, 2010; Skolbekken, 1995), surveillance of women through diagnostic processes can be deconstructed as a medical and public health coercive practice (Turner, 1992a).



Finkelstein (1990) argued that individuals have tacitly agreed, as a condition of being normal, acceptable and responsible members of society, to being surveyed and measured by the calculating medical eye, and to the implicit use of this information to further strengthen medical bio-power.

*There was even a medical student there, even though I was asked if I minded about that. And of course you say you don't mind because they have to learn somehow don't they? And it may as well have been my body than anybody else's!*

Nancy

Foucault's (1973) notion of medical diagnostic surveillance was clearly shown in Nancy's experience of the institutionalisation and apparatuses of the medical generalist's surgery, breast clinic or hospital. The clinical gaze, as Foucault argued, is located in clinical observation and hospital-based medicine, physical examination and the incitement for the patient to 'confess', in Nancy's case, by uncovering and exposing her breast for observation and assessment. Thus the diagnostic setting with its fixed stare on the female breast, had become a place where large numbers of docile non-resistant, and altruistic patients like Nancy passed under the gaze of a relatively few clinicians. The medical gaze had extended beyond interpersonal consultation, the human touch and physical examinations to further involve Nancy with complex and impersonal medical apparatus and unfamiliar specialists.

The extent to which biomedical understandings permeate and dominate contemporary discourse on the body and "provide the main framework through which bodies currently become intelligible" (Harding, 1997, p. 145), was conversely also a comfort for Nancy. She found herself in a position of trusting the legible and intelligible diagnostic powers of breast oncology. It was scientific knowledge that had invested and entitled health professionals, as bio-politicians, to control the boundaries of normality and thus to construct Nancy's breast as 'normal' or 'healthy', 'abnormal' or 'diseased'. Medicine was coercive of Carol and Nancy in the sense that its practices discipline individuals, patients and the healthy alike, through its forms of surveillance over everyday life. The normative coercive institution of medicine (Foucault, 1980) exercises a moral authority over the individual by diagnosing individual disease and providing treatment in an authoritative way, but one which is readily accepted as legitimate and normative at the everyday level. As a result, it was Carol and Nancy's knowledge about the positive power of medicine's technology which made them seek diagnostic knowledge about

their own breasts. In their accounts, can be seen application of Foucault's (1991) concept of the enterprising or active self. While the techniques of power operating on the women were not repressive, but productive and exercised through the social body, the exercise of power was strategic. The medical discourse of diagnosis had gained such dominance in their understanding of health and illness that it had shut down all possibilities for Carol and Nancy, and indeed for all of the women in this study, other than to seek a diagnosis.

### **The Gender Discourse of Diagnosis**

In the last two decades, research into language and gender has moved from essentialist approaches which treat male and female as discrete social categories, to social constructionist and performative approaches (Butler, 1997; 1999). Current approaches focus on the dynamic ways in which people draw on discursive resources to construct their social identities and the identities of others, especially gender identities in different social contexts (Holmes & Marra, 2010). Gender discourse is the discursive constructions and practices deployed by the speakers, which they bring from broad societal norms of gendered ways of thinking and behaving. As Eckert and McConnell-Ginet (2003) point out, we orient to societal, gendered norm "as a kind of organising device in society, an ideological map, setting out the range of the possible within which we place ourselves and assess others" (p. 87). When applied to the diagnostic process in the breast cancer experience, gender discourse can be conceptualised as the inherited structures of gendered beliefs and power which both enable and constrain the speakers within the specific context of interactions between health professional and patient (Ussher, 2007; Watkins & Whaley, 2000).

### **The Gender Discursive Object – The Woman with Breast Cancer**

The woman who receives a confirmed diagnosis of a cancerous tumour in her breast is the discursive object of gender discourse. This construction shifts the gaze from the pathological and medical construction of the tumour, to the woman and her gendered body. The gaze is on her as a woman being a woman, with uterus, womb and breasts, and with breast cancer.

*So there I was, a woman with breast cancer. Breast cancer is the most common cancer of women, so you sort of expect that if you are going to get anything serious, there's a high chance it will be that. It's most definitely a girl thing.*

Jo

Jo was immediately constructed as the discursive object of diagnosis through a 'gendering process' (Eckert & McConnell-Ginet, 2003), the product of social practice. She identified herself as a woman diagnosed with what is constructed as predominantly a disease of the female sex, and described the diagnosis as almost expected. Her comment indicated the intersection of the medical and gender discourse. In many ways the medical discourse, the public health discourse of health promotion, and gender discourse construct the man or woman as sick or well as a result of gender, and categorisation by sex (Harding, 1997). These three discourses predominantly construct bodies as sexed in detailing their risks of succumbing to diseases like prostate cancer and breast cancer. Female bodies, more so than male bodies, have become medicalised by sex. This is seen in the sense that so much of essentially female anatomy, for example the uterus, womb, cervix, and breast, and normal, natural physiological functions such as menstruation, pregnancy, childbirth, hormones and menopause commonly require specialist medical attention.

Feminist writers on women's health (Butler, 1990; Ussher, 2007; Watkins & Whaley, 2000; Zita, 1988) have criticised the medicalisation of women's lives, and its contribution to women's subjugation. However, all three discourses of medicine, public health and gender are firmly ensconced in the female psyche. Zita (1988) in particular, conceptualised the processes of diagnosing female illnesses and diseases as activities whereby subjectively expressed meanings are quantifiable symptoms sharing a common pattern of female bodily functions. For Jo, getting breast cancer was "a girl thing".

Not only was the woman diagnosed with breast cancer constructed by the sex and gender discourses as a female with a diseased sexual organ, she was also constructed by some of the health professionals as having the tendency to respond to the bad news in ways considered characteristic of feminine emotional instability (Ussher, 2011).

*Personally, I get very anxious about having to give a diagnosis of breast cancer. All women are shocked, and some react in strange ways. I've even had some take their anger out on me. Some women, quite a few in fact, tend to become hysterical; not in an insane way, but do weep loudly, some even howl in that awful way you see in some cultures when a woman is deeply anguished. That howl is chilling for any doctor.*

Oliver, GP

*Sometimes with women patients it seems that the womb and the breast and the head are all mixed up together. We know the hormonal connections between the gynaecological bits, but some women once diagnosed with breast cancer, never give it up. It seems to become almost a sickness in the head.*

Charles, Breast Surgeon

Medical literature refers not only to ‘heart-sink consultations’ but also to ‘heart-sink patients’ (Moscrop, 2011). These are difficult, dysphoric patients, labelled “hysterical” by Oliver, who evoke anxiety, fear, despair, anger or frustration in some health professionals. Oliver and Charles perceived their female patients to be catastrophising, not processing information efficiently or calmly as was expected of them, or being overly pre-occupied with their medical status, which was not acceptable. Such women were feared by Oliver and Charles because they made them feel very anxious about being on ‘the receiving end’ of women’s distress. Oliver and Charles discursively constructed the woman diagnosed with breast cancer as the hysterical woman, in interactions which were stressful and difficult for them to manage. Charles’ comment could also be seen as illustrative of the continued patriarchy of the male doctor and the female patient. He made reference to the hormonal makeup of the female, and in a demeaning way, albeit unconsciously, constructed parts of the female body as “bits”. His particular construction of women’s difficulty in coming to terms with breast cancer reflected the continued patriarchal positioning of some male physicians to the discursive object of the female body and psyche.

#### **The Gender Subject Position of the Woman Diagnosed with Breast Cancer in 21<sup>st</sup> Century New Zealand Society**

The process of gendering or gender performance takes place within specific communities of practice, such as the family, and emphasises specific facets of members’ social positions and different dimensions of social meaning (Baxter, 2003; Cameron, 2009). Breast cancer is a significant disease of women, and its diagnosis brings another different role and speaking position for the woman within society. Some of the women in this study interpreted their new position as a threat to the well-being of their family, often reinforced in their health professional’s thinking (Duschinsky & Rocha, 2012).

*To find myself in that position – diagnosed with breast cancer certainly changed my perspective. I immediately thought of my family. That was a very tough bit – breaking the news to my family. I didn’t want to die. I didn’t want to leave them in such an awful way.*

Nancy (in tears)

*It can be a very sensitive issue, talking with some women about, and physically examining, their breasts, but my philosophy in this game is - save a life, save a mother, save a family.*

Michael, Breast Surgeon

Historically, women were ascribed a specific identity by men and positioned within the spheres of nature, emotion, desire and the household. All four spheres are intimately related to the gendered symbol of the female breast. For Foucault, the feminine body is saturated with sexuality, its pathology intrinsic to it. The female body is the embodiment of the true 'social body' – family, children, mother, and "nervous woman" (Foucault, 1978, p. 104). As Charmaz (1983, 2006) portrayed it, our concepts of 'self' and social position are constructed through the social relationships we have with others. This is a life-long social process with daily validation. Nancy knew immediately that her "position" as she called it, had changed to one which she interpreted as putting her family at risk of losing a key member. She thought of her family first, putting their feelings and welfare before her own. She was very definite in her interpretation of the diagnosis as a threat to her and her ability to continue to perform the many roles expected of her within her family.

Michael, while acknowledging the sensitivity of the diagnostic process for women, constructed by him as a "game", positioned himself as the saver of an individual life, and the life of an intact family. Turner (1996), made a suggested correlation between Foucault's construction of women's bodies and the peculiar conjunction of social structures which have produced the contemporary crisis and threat of breast cancer to modern family life. Futures can no longer be taken for granted.

Anxiety related to the threat to one's social position of the critical role of mother and partner, as articulated by Nancy, was emphasised in general terms in a pertinent newspaper clipping.

"... As a woman I care passionately about the health of my breasts and that of my children, grandchildren and of women in general. They provide me and my husband with pleasure, have been instrumental in nurturing my children, and are an integral part of my self-image as a woman. Women now seem to be in a state of fear. Breast cancer is widespread and they feel impotent and helpless to improve their chances of a long and healthy life" (Sunday Star Times, Focus, November 7, 2010).

There is an integral balance between one's awareness of one's daily social position and of one's future self. Most people are accustomed to thinking that they will be mostly unchanged from one day to the next in their adult life, believing in the future, and expecting each day to be broadly like another. Although there is an awareness that one day life will end, there is hope for a future to a relatively advanced age. Those who 'fall ill' suddenly as the result of being diagnosed with a life-threatening disease, like all of the women in this study, can experience a rapid and traumatic change in their sense of position and self (Charmaz, 1983, 2006), as so movingly described by Nancy.

### **The Gender Subjectivities of the Woman Diagnosed with Breast Cancer**

A diagnosis of breast cancer usually comes suddenly and unexpectedly (American Cancer Society, 2013). Because it is not easily observed in the early stages, and has a tendency to spread to different parts of the body, it seems difficult and complex to control, and, in comparison to other diseases, stands out as unusually menacing. A diagnosis suddenly and dramatically constructed new identities for the women in this study, while simultaneously taking away others.

*That I was going to be half a person was my reaction. That it must be the worst thing that can happen to a woman.*

Stephanie

Illness was an experience through which the women learnt new definitions of self and often relinquished old ones (Charmaz, 1983, 2006). Stephanie's difficulty, by drawing on medical meanings of breast cancer and its treatment, was that she suddenly faced the possibility of annihilation by her own body. Without warning, the tumour was constructed not only as a threat to her physicality, but also to her identity as a 'whole' woman. She was now facing a potentially fatal illness, mutilating surgery and an overwhelming change in self-estimation. Stephanie showed that a woman's identity can be greatly affected by what suddenly happens to her. The risk to life, physicality and femininity created for her an identity which was both threatening and alarming in a number of complex ways. The loss of her former self was a frightening experience, and a grieving process, exacerbated by the narrow, medicalised view, which ignored or minimised the broader significance of the fear experienced by her as a newly-diagnosed woman. For the women like Stephanie, their former, strongly gendered self-images were abruptly taken away with the simultaneous emergence of new, less secure identities.

In Foucault's (1980, 1982a, 1984, 1991, 2000) analyses of power and politics, he examined how emotions are constituted and managed, that is, under what circumstances emotions are considered appropriate or inappropriate, and how they function in power relations (Schutz & Pekrun, 2007). This gaze on emotions has been termed by at least one Foucauldian scholar as the 'emotional turn' (Tamboukou, 2003). Although he did not engage directly with feelings, Foucault considered emotions to function simultaneously as a sign of power and as one of its effects. He viewed emotions as discursive practices, historically and culturally constituted - both as ways of knowing within particular settings, and as distinct realms in which meaning is constructed. As I described in Chapter Two, discourses do not simply reflect or describe reality, knowledge, experience, self, social relations, social institutions and practices, but rather play an integral role in constituting (and being constituted by) them. In other words, discursive practices establish what can be felt. In and through these discursive practices individuals ascribe to themselves body feelings, intentions and all other psychological attributes that have for so long been attributed to the unified self (Schutz & Pekrun, 2007, p. 297). In this sense, the women in this study and the health professionals 'did' or enacted their emotions; their emotions did not just happen to them. In the enacting, new subjectivities were opened up (Rose, 1990). All of the women stated that they were shocked to receive the confirmed diagnosis, and immediately felt fearful. The intersection of medicine and female gender was a place of considerable subjective emotion for these newly-diagnosed women.

*I sat in a small sterile medical changing room, alone, frantic with emotion. I felt old and some-how defeated. It seemed like it was just me, a little old frightened woman up against it all. I didn't feel brave at all, like the stories of other brave women.*

Kim

Kim, finding herself as a woman in an unfamiliar, clinical setting, with no womanly trappings, was alone, overwhelmed, and very fearful. She referred to her age, and compared herself to the gendered stories of other women, constructed by her, and frequently by medicine and society, as heroic. There was an ambiguity in her perception of herself and female enterprise, because she was oppressed by her setting, which was subjugating rather than enabling.

My analysis also showed that there were other equally revealing types of gendered identities which the women assumed in relation to the diagnosis of breast cancer.

*There was something different, extraordinary about it. I did wonder why it had to be me. There was no-one in my family who had had breast cancer. I sort of felt singled out. I wondered whether it was a punishment for something I'd done wrong. I wondered what I had done wrong to get breast cancer. I wondered if it was because I hadn't had children.*

Agnes

Agnes showed that when confronted with a serious illness like breast cancer, some of the women initially engaged in some kind of exploration of themselves as the origin of the disease (Houldin, et al., 1996), and assumed identities which were self-deprecating and castigatory. The more serious the illness and the threat, the more necessary it seemed to them to undertake such an exploration (Shaver & Drown, 1986). This behaviour can be variously discursively deconstructed as logical or illogical, or a mixture of reason and unreason, knowledge and ignorance, involving emotions of various kinds. However, for the women in this study, such self-exploration functioned as an attempt to create some kind of rationalisation in the chaotic experience that followed their diagnosis. Agnes searched within her family for a genetic link, and not finding one, considered that not bearing children was the reason for the penalty of disease and illness – a re-emergence of the gendered construction of 'nuns' disease'. Many of the women talked about their lives before the diagnosis as the epitome of happiness, health, and fulfilment. For many like Kim and Agnes, the diagnosis created subjectivities of the punished, blameworthy, solitary, troubled and/or fearful woman.

### **The Gender Discursive Practices Relating to Diagnosis – The Active or Inactive Woman**

A diagnosis of cancer is arguably a significant emotional challenge. Popular discourse has shown it to be one of life's most dreaded personal crises (Lerner, 2001). For the woman diagnosed with breast cancer, the initial prospects can be daunting (Holland & Lewis, 2000). It was not surprising then, that the course of the diagnostic process revealed a replication of the dichotomy of the women's passivity versus activity, seen first on the discovery of symptoms, which I described in Chapter Six.

Most of the women felt a strong need to overcome the threat and to regain control of their lives. The woman who acted quickly to understand her diagnosis, to share it with significant others and to be willing to move on rapidly to treatment was, again, positioned at the intersection of medical and gendered practices.



*I decided to act swiftly and decisively, to tell my family and to trust the specialists to cure my illness. I wanted that lump out, and the sooner the better.*

Rose

Rose trusted the knowledge and power of medicine to accurately diagnose, treat and cure her. In her role as mother, she also acted quickly to inform her family of the upcoming disturbance to family life. Her intrepid focus on her illness and vehemently-expressed desire to be cured, thereby reclaiming her healthy body, exemplified the Foucault's (1970) notion of rationality – the 'reasoned subject'. Health became, at least in part, the responsibility of Rose to be accountable to herself and to others.

In contrast to the women who rapidly engaged in the diagnostic process and who strove to make sense of the reality of the confirmed diagnosis, others reacted in opposite ways. These discursive practices were mostly disengagement, particularly seen in what some professionals termed "avoidant and risk-taking" behaviours, exhibited when facing the large threat to all aspects of their lives and roles as women.

*I didn't want to think about an operation at first. Probably most other women would not have thought like me. I couldn't face the disruption to our lives this was going to cause.*

Linda

*I did not tell them (her adult children) straight away that I was going to have a mastectomy. I don't know why I wanted to keep it a secret; I guess I wanted to spare them until after the operation.*

Kim

Linda and Kim were positioned at the intersection of the medical discourse which labelled their behaviours as evasive and hazardous, and the gender discursive practices of protecting their families. Like Kim, Linda compared her behaviour to that of other women. Putting others' needs first was a gender construction (Aspinwall & Straudinger, 2003; Keyes & Haidt, 2003; Watkins & Whaley, 2000) characteristic of many of the women's attitudes to difficulty or distress. Just as on the discovery of symptoms, such discursive practices were often linked to behaviours of delay. Linda and Kim's attempts to conceal or to delay telling others were used as a shield against the frightening part of their new reality.

In a general sense, families often talk of honesty, of having no hidden truths. If there are any secrets the association between secrecy and family satisfaction is influenced by the

form, topic and function of the secret (Vangelisti, 1994). Whether society constructs concealment and delay as responsible or irresponsible discursive practices, a diagnosis of breast cancer was shown by women in Rose, Linda and Kim's position to be a challenge to these family principles.

There were also gendered ways in which some of the women were expected by their health professionals to behave. Failure to do so resulted in a blaming attitude towards them.

*Sometimes I get bloody angry. Women who don't go for regular screenings should be made to feel guilty. It's all very well them turning up here, and turning a bloody act on when the news isn't good, but I do blame them. There is enough publicity about all of this.*

Ross, Oncologist

Ross's anger at his patients who did not voluntarily and regularly undergo the medical surveillance of mammography screenings, and who were later diagnosed with breast cancer, reflected a gendered construction of the irresponsible woman. He felt intense emotion about women's inactivity in self- and medical and public health surveillance, which were discursive practices constructed by medicine as life-saving in most instances. Ross cast blame and guilt on these inactive, irresponsible women, putting the onus back on them for eventually developing breast cancer. There was a strong trace of the gendered hysterical woman in his comment.

### **Gender Techniques of Power in Diagnosis**

Gender can overlay and complicate the power relationships between doctor and patient (Code, 1995; Goodyear-Smith & Buetow, 2001). Clinical and social locations, defined by Code (1991, 1995) as 'rhetorical spaces', such as a doctor's surgery or a breast clinic, have implicit tactical rules of power which govern how and why things are said, and how behaviour is interpreted. In this study, interactions were be facilitated or made more difficult by the perceived quality of the communication between some of the women patients and their health professionals.

*A needle biopsy. A needle in the breast. Even the words are painful. A needle is used to sew something up or prick something. I felt that he [the male oncologist] actually was a bit of a prick. Bow tie and preening. He seemed very dismissive. He was not listening. I was asking questions and he wouldn't*

*communicate. He gave very short answers, just yes or no, without explanation, and I felt like I was being treated as another stupid female.*

Diane

*It was great to have a woman professional present when I got my diagnosis. Breast care nurses are very good; they understand breast cancer from a woman's perspective, and are there immediately afterwards to talk, and also available by phone after the bad news has sunk in.*

Mimi

*I get told by patients that the behaviour of some of the medical people women meet has been less than supportive. Now you've got me thinking. There are some tossers in bow-ties of course, and it's easy to see how their individual choice of dress-code can be construed as their self-perceived power and status within medicine.*

Oliver, General Practitioner

In the social location of surgery or clinic, some interactions between a male doctor and the woman as 'female patient' were perceived by some as power-induced by the doctor and disempowering for her. Diane noticed her health professional's limited interest or understanding of her as a woman. She constructed both the physical process of the biopsy and the oncologist's social manner and his dress as distancing, and combined them in a way that she perceived herself to be treated in a gendered negative way (Eckert & McConnell-Ginet, 2003). His demeanour and the medical process he performed were factors which Diane felt were patronising, and over which she had little power or control. This led to her belief that possible clinical explanations had been omitted and that the consultation had been inadequate and humiliating. In contrast, some of the women found strength and support in interactions with professionals who were also women. Mimi held a gendered conviction that female health professionals understood women patients better than male professionals did (Bordo, 1990). Oliver's statement illustrated how there was potential for the gendered personal experiences, idiosyncrasies and interests of doctors and patients to be dangerously misinterpreted.

Diane, Mimi and Oliver together reflected the pervasiveness of gender influence in doctor-patient interactions. Gender was a powerful ruling force in Code's (1995) rhetorical spaces, and the gender of the health professional, as well as that of the patient, partly explained why misunderstandings occurred between the two parties in this study. The accounts of Diane, Mimi and Oliver demonstrated the extent to which discourse

played an important part in the construction of the gender order within the women's experiences of breast cancer.

## **Summary**

In this chapter I have identified and analysed the dominant discourses by which the women participants and the health professionals constructed the diagnosis of breast cancer. While this analysis involved the same group of women and health professionals, the health professionals naturally became more prominent in the diagnostic process than they had in the discovery of symptoms. Because of the specialisation of oncological diagnostic medicine, there were several different types of professionals moving in and out of the women's lives during this stage of the breast cancer experience. Diagnosis was a language of medicine (Mishler, 1984), and was in itself a discursive practice. In this chapter, the impact of the certainty that a confirmed diagnosis had on the women who received it, and on the health professionals who imparted it, was explored.

The analysis identified two dominant discourses by which the speakers constructed the experience of diagnosis – the medical discourse, and the gender discourse. These were the same two discourses by which the women constructed the discovery of symptoms, described in Chapter Six. In the first instance, the process and categorisation inherent in the making and imparting of a diagnosis of breast cancer was deeply imbedded in the medical discourse and the associated power tactics of medical surveillance. The diagnosis process was central to the power and social control of the women, because giving a name to the symptoms was the starting point for the construction of the medical sign, and of them as medical patients. It located the parameters of normality and abnormality, demarcated the professional and institutional boundaries of the social, and authorised medicine to label and deal with them on behalf of society at large.

The discursive object was reconstructed from a lump to a tumour, a symptom to a sign, and the medical discourse constructed the tumour as dangerous sign. Diagnosis placed the women on the medical trajectory, making them dependent on seeking meaning of the tumour from specialists or expert readers of their bodies. They were now constructed as medical 'patients', and assumed the subjectivity of 'cancer patient', which engendered in them considerable fear. As a responsible citizen the women submitted to medical surveillance, and either shared the confirmed diagnosis or concealed it. The main discursive practices of the health professional were to perform the diagnostic process, to interpret results and to impart the findings.

Diagnosis was also a medical technique of power, through the medical surveillance of complex technology and machinery which classified, categorised and differentiated a woman's breast from the normal. The ability to diagnose and impart information about breast cancer, gave the professionals considerable power in the doctor-patient relationship, but this power was frequently accompanied with apprehension. Some professionals were involved in what medical discourse constructed as 'breaking the bad news'. For most of the professionals, the imparting of a confirmed diagnosis engendered anxiety about their patient, and for some, the idiosyncratic emotional reactions of both or either parties resulted in stressed interactions.

While the diagnosis was constructed by medical discourse as a given biomedical fact, its imparting also set in motion complex gendered understandings, meanings and relationships. The gender discourse constructed the diagnostic process differently, but also with emotional effects. The sex discursive object was the woman, the female, with uterus, womb and breasts, but hers was also the gendered docile female social body, needing medical attention to keep it alive, and to allow her to continue to function in her female roles. Her subject position was that of a woman, in society, with breast cancer. Most especially she was a key family member, and the gender discourse constructed breast cancer as a threat to her and her family. The diagnosis process for all of the women revolved around the certainty of diagnosis and uncertainty about the future. The women in this study either disclosed or concealed their diagnosis, taking up stances of determination or pragmatism. Being in this situation produced significant fear, and gave rise to a mixture of discursive practices and identities including guilt, self-blame and punishment by the women of themselves, and the over-dramatic, hysterical female by some of the professionals. The gender techniques of power overlaid and complicated the power relationship between these women and their male health professionals.

The overall finding from the analysis presented in this chapter, I argue, was that the process of receiving and imparting a confirmed diagnosis of breast cancer was both a discursive practice and a form of medical surveillance, which when combined with the gender constructions of the experience of diagnosis, engendered considerable fear in the women and apprehension in the health professionals.

In the next chapter, I identify and analyse the dominant discourses by which the study participants constructed the *treatment* of breast cancer. I explore the women's experiences of undergoing treatment, and integrate the perspectives of the professionals

who provided such intervention and care. The discursive technologies of power, and the subject positions, subjectivities and discursive practices which emerged for both parties as a result are also examined.

## CHAPTER EIGHT: THE DISCURSIVE FIELD OF TREATMENT

### Introduction

In this chapter I explore the discourses which became most dominant during the *treatment* stage of the breast cancer experience, and the impact on the women and health professionals as a result of their positioning and being positioned in these discourses. The providing and receiving of treatment for a serious disease like breast cancer were the main discursive practices of the health professionals and the women at personal, dyadic and group levels. The medical discourse constructed different forms of pathological breast cancers requiring different treatment regimes, and opened up different spaces for the emergence of different medical specialties professionals involved in these treatments. Diagnosis determined the type of treatment the women were prescribed, and as a result they interacted with a much wider range of professionals than during the discovery of symptoms or diagnosis.

In their undergoing treatment for breast cancer, all of the women engaged with unfamiliar technology and mostly unfamiliar health professionals who administered to them. The disease of cancer, and its resultant illness manifestations, has been commonly constructed in the media and by medical discourse as, amongst many other things, a disruptive force (Galgut, 2010; Holland & Lewis, 2000). As a result of her deployment of this discourse, the woman, now positioned as patient, construed herself as having lost control of her body, or of her body taking charge with symptoms that dominated and required restorative treatment. It was in this sense that the women confronted unknown, bewildering and unsettling treatment options and experiences.

My analysis showed, not unsurprisingly, that the discourse which most predominantly constructed the three main initial treatments for breast cancer (surgery, radiotherapy and chemotherapy), was the medical. However, there were also gendered meanings of treatment for both the women and the health professionals. Being positioned by these two discourses separately and at their intersection produced, I argue, considerable emotional reactions in both parties.

### The Medical Discourse of Treatment

As noted above, there are currently three main immediate medical treatments for breast cancer. Surgery, radiotherapy and chemotherapy can be employed singly or in various

combinations. Mostly these treatments are administered in sequence, and are often followed with pharmaceutical intervention. The discipline of oncology is firmly based in the bio-medical model, and the provision of cancer treatment is constructed as fundamentally a clinical decision-making and procedural issue (Bartlett et al., 2011). Each type of treatment has its own oncological focus, purpose, and method. Health professionals' work places are often in institutional settings with large medical teams with multiple missions. Each team, discipline, or individual staff member, specialises in and applies their own facet of treatment of the cancer or care of the cancer patient (Blazey et al., 2006).

In the following section of this chapter, I present descriptions of the three main medical treatments for breast cancer that the women in this study underwent. Bearing in mind that because these three very different treatments were in themselves discursive practices, (Foucault, 1972, 1973) each of them provided spaces for the emergence of different identities, subjectivities and practices. Both the women and the professionals positioned themselves, and were positioned in relation to the medically-constructed event of invasive cellular breast cancer. Each of the three treatments was an example of a medical technique of power. This was seen especially in the specialist discipline of oncology, and in the power relationships between the women who had to submit to treatment and the health professionals who administered the different forms of treatment. As indicated above, the three treatments the women in this study underwent, whether separately or in combination, were surgery, radiotherapy and chemotherapy. I briefly describe each of them in the following section.

The medical archive shows that surgery is the oldest recorded form of breast cancer treatment, and continues to play a central role today (Fisher & Gebhardt, 1978; Mukherjee, 2010; Olson, 2002). Surgical treatments include lumpectomy (also known as wide excision or partial mastectomy, involving the removal of the tumour and some tissue margin), axillary node dissection, (with eight or more armpit lymph glands removed), total mastectomy or removal of the entire breast, modified radical mastectomy or removal of entire breast and some axillary nodes, and full radical mastectomy with removal of the entire breast, some axillary nodes and chest wall muscles (Carlson et al., 2009).

Radiotherapy is viewed by medicine as an indispensable treatment method in the practice of oncology. Some breast cancer patients undergo radiotherapy as one



component of the treatment along with surgery or chemotherapy or both (Carlson et al., 2009). The discursive object of the radiotherapist's gaze is different from that of the surgeon's because the cancerous tumour has been removed by surgery, but the risk of spread of cancerous cells throughout the patient's body remains high. The focus is now on the cellular and invasive nature of cancer. However, radiotherapy affects normal tissues as well as the neoplasm, and the challenge for the radiation oncologist and technician is to target tumour cells and spare healthy tissue. Therefore, meticulous attention to proper geometric planning is a critical part of radiation oncology. Each plan requires individualised computer-assisted dosimetry, with small tattoos being indelibly inked into the patient's breast and chest skin in order to facilitate consistent positioning and delineation of the field of each megavoltage treatment. The total treatment for breast cancer is divided into fractions generally delivered daily five days a week for six weeks (Cuzick, 2005; Liggins Institute, 2013; Lipmann, 2011).

The most common and best-known systemic form of breast cancer treatment is chemotherapy (followed by hormonal therapy and immunotherapy). Chemotherapy is the treatment of cancer with one or more cytotoxic antineoplastic drugs ('chemotherapeutic agents') as part of a standardised regimen. Chemotherapy may be given with a curative intent or it may aim to prolong life or to palliate symptoms. It is often used in conjunction with other cancer treatments, such as radiotherapy or surgery (Cuzick, 2005; Joensuu, 2008; Lind, M., 2008). The effectiveness of chemotherapy in metastatic disease is seen in its major implementation prior to operative treatment (neoadjuvant) or immediately after surgery (adjuvant). Among the tumours in which these two types of chemotherapy have substantial benefits is breast cancer.

### **Medicine's Discursive Objects – Cancer and the Objectified Body Part**

As I described in Chapter Seven, the medical discourse constructed cancer as a malignant cellular disease which could become invasive and spread through the lymphatic system to other parts of the body. The medical discourse constructed breast cancer particularly, as a potentially curable or manageable condition if diagnosed early enough and treated by medical means. As to be expected, in this study the focus or gaze of the specialists was on the cancerous tumour and its precise location within the breast. However, further deconstruction of the participants' accounts showed that it was perhaps in the technologically sophisticated treatments for breast cancer, especially mastectomy, that the impact of the medicalisation and objectification of the female body was most clearly seen.

*That special bit of my body was separated out and talked about in a disconnected way. I felt as if I was a biological specimen. I felt as if my breast was being treated as an impersonal body part being “offered up” to the specialists.*

Nancy

Nancy's experience reflected how medicine objectified the breast in the manner of any other body part, isolating it as an identifiable object apart, separate from the woman. Nancy's breast, emotively described by her as “special”, became special for oncology in a different way – a biological object, a sample within a docile body (Foucault, 1977). The objectified breast facing treatment was a relatively uncomplicated medical construction for the surgeons interviewed for this study. Nancy's comment revealed the medical objectification of her breast, constructed as diseased, discrete and impersonal, with the tumour under the gaze of surgical intervention.

#### **The Subject Positions of the Woman Dominated and Exposed by Medical Treatment for Breast Cancer**

There were significant complexities for the woman facing treatment for breast cancer. She was now positioned as a patient dominated by cancer through the intense focus by medicine on the cancerous tumour and its elimination, and by the management of metastasis. The concentrated gaze on her breast continued the physical exposure beyond that in discovery and diagnosis. This was an experience which some of the women found considerably uncomfortable.

*I felt overpowered and fearful by the fact that I had to have surgery. Talk of the tumour, its size, feel, and the threat of it seemed to take over all other conversation. I lay there in a shapeless gown with a front opening which exposed my breast and my soul.*

Anne

*I come from a background which was sheltered and prohibitive. Even though we don't talk about it, I think that, just like during examinations, screenings and diagnosis, it is somewhat difficult for most women to expose their breasts to unfamiliar specialists.*

Mary


### **The Discursive Construction of Surgery**

Intimate applications of treatments to the breast significantly complicated the relationship between some of the women and their specialists. The vulnerabilities of exposing intimate body parts brought both parties into an existentially charged situation requiring trust by the woman and careful management by the professional (Williams, 2005). For Anne, the tumour itself was all-dominant. Life and talk were overshadowed by a tumour which must be removed surgically - a body part objectified by medicine which required intervention from skilled operators and technicians. She was overwhelmed and alarmed by her loss of control over her body and health, the tumour being the centre of attention. By the nature of medical treatment's intrusiveness, Anne felt that she was placed in the position of baring her very soul. Mary showed that women from certain backgrounds can find it difficult to accept the physical exposure required by treatment. Some of the women participants had great difficulty exposing their breasts to doctors. The tensions generated for Mary about exposing her breast to specialists and technicians for treatment was acute. Both Anne and Mary were positioned strongly as 'the patient', the recipient of treatments focussed solely on the removal of the cancerous tumour (Zola, 1973). The breast, once private and special, had become very public.

A practice of the medical discourse was that most of the women, on facing and receiving treatment, had many frightening ideas about it. As the result of the discovery of symptoms and confirmed diagnosis, all of them had, up to this point, faced the larger issues of a life-threatening disease, and having to submit to on-going treatment strongly reinforced their position as the woman dominated by breast cancer.

### **The Discursive Construction of Radiotherapy**

Radiotherapy itself aroused even more anxiety. While radiotherapy is a very different type of treatment from surgery, undergoing radiotherapy treatment also positioned the women strongly as the medical patient and as the recipient. As with surgery, the docile woman's body again became dominated by medical discourse and practices which left her vulnerable and unprepared. Because of its highly technological nature, all of the women approached radiotherapy treatment with fear or at least apprehension, and some experienced significant anxiety about many aspects of the ways in which it was administered (Cuzick, 2005).

There's a nuclear sign  on the door '**Danger! High Voltage! Do Not Enter!**' Lying there all alone, in a dark room, with all these machines looming over you, making weird whirring noises. It is quite unreal. Like nothing else I've ever experienced really. There's something ghastly about it all. It was all quite frightening, and I felt really alone and scared.

Bev

*I felt as if I was hermetically sealed in with big, frightening apparatus, watched by faceless people. You have to lie there very still until they let you out again. I lay on my back and felt the tears trickling down the side of my face, and into my ears, and I could not move to wipe them away.*

Linda

*Having radiotherapy is strange really. It's not like going into hospital for an operation, over and done with. You have to keep going back and back every day. Because you come and go, it becomes part of your usual day's schedule, at the same time every day, so you can't forget that it is connected to something as serious as breast cancer. In that way, radiotherapy continues to keep the anxiety levels up because you're not given time to recover.*

Bev

*You knew exactly how many treatments you were going to have so you just counted them down. Marked them off with a strike through the days on the calendar. Wishing your life away in order to get it back.*

Susan

*I'm a farmer's wife, so with each treatment timed at every seven minutes, it seemed to me that we were like sheep through a dip, and like the mindless sheep who follows the one in front, into something fairly poisonous.*

Carol

The accounts of these four women revealed the passivity of their positioning, breasts laid bare and subjected to formidable technological power. Bev's comment illustrated how the scientific construction of radiation conjured up for her images of atomic power and radiation. She deployed in the first instance, the scientific construction of radiation as potentially dangerous and destructive, and was overwhelmed and frightened by the technology and clinical setting in which she found herself. Her account offered insights into the significantly frightening experience for her as a patient undergoing the highly specialist area of radiotherapy treatment – isolation by technology. Linda likewise was

distressed by technology's capacity to separate and immobilise. Both women talked about feeling overwhelmed and imprisoned by the large machines, and anxious about the closed space of the treatment setting. Linda was distressed by her aloneness and her inability to wipe away her tears because of her 'fixed' position. Bev, Susan and Carol also revealed anxieties related to the scheduled nature of their treatments – a medical technology of power over which they had no control.

### **The Discursive Construction of Chemotherapy**

The practice of the scientific medical discourse's engendering of apprehension was equally true of some of the women's experiences of chemotherapy. Most of the women had, at least initially, limited knowledge regarding chemotherapy, and this led them to being positioned in places which gave rise to anxieties about how it was to be administered, and about immediate and long-term effects.

*I anticipated that I would vomit for weeks on end and lose all of my hair. There are awful images of women in this state. And it was just as bad as I had dreaded. Too sick to care ... I was too sick to care.*

Rose

*The idea of a combination of drugs made me I feel as if I was being experimented on - a bit of a hit and miss approach. My husband said that I was just a guinea pig.*

Jo

Rose's excerpt indicated the power of anticipation of events based on the common constructions by others. Jo, again, demonstrated feelings of lack of control over oneself imposed by a specific medical treatment regime. Patients' prior knowledge about chemotherapy is often derived from others' personal experiences and from the media (Good, 1994; Holland & Lewis, 2000; Rosenbaum & Roos, 2000), whose content might be out-dated and/or dramatised. These limited sources of information led to Rose and Jo's attitudes and fears.

Exposure to radiation and the handling of chemotherapeutic drugs require strict safety measures to decrease risks to the health of technicians (Cuzick, 2005; Joensuu, 2008; Lind, 2008), so the practice of radiotherapists and chemotherapists gowning up and wearing protective apparatus rendered them impersonal and scarily featureless to the women, as commented on earlier by Linda. Radiotherapy and chemotherapy raised the issue of patient ambivalence. In order to be made well by medical means the women

had to expose themselves to something which they regarded as dangerous, and which day after day left its physical and/or emotional legacy. In various ways, they revealed their fears about pain, scars or marking, the tattoo, somatic side-effects, the chances of sterility and of affected off-spring. A lot of the fears they cited were about “badly burnt” and “burnt up”. All of the women in this study who received radiotherapy and/or chemotherapy spoke about experiencing considerable emotional conflict and anxiety even though they were being administered potentially curative medical treatments. This was because, paradoxically, these treatments are based on scientific theories of radiation and systemic poisoning, both of which are viewed in general terms as very harmful and damaging (Cuzick, 2005).

### **The Subject Positions of the Health Professional as Treatment Provider**

The upholding of dignity for the body and the integrity of the patient are legal and ethical principles upon which all medical practice is based, and on which patients have a right and expectation to depend (Beauchamp & Childress, 2001). While from the women’s perspectives, it seemed that the objectified medical gaze did not see beyond the emotional issues for them when facing treatment, in fact, some of the medical professionals were very mindful of the embarrassment exposure of the breast might cause women.

*I know that it is difficult for some women to expose themselves in such a way. Of all the body parts to have to uncover, the breast is one of the most difficult I think. I know that there are issues for men with male illnesses, but with women it seems so much more intimate. Obviously I try to make this as easy for them as possible.*

Michael, Breast Surgeon

Michael was positioned within the medical discourse as the intimate practitioner, and he was respectful of his patients’ feelings while he was in this role. His subject positions were those of neutrality and technical competence, in the skilful application of his medical knowledge to his patients’ problems. The medical discourse had granted Michael privileged access to women’s’ bodies in ways that would be off-limits in other circumstances (Bradby, 2012). This was particularly so in breast cancer, where Michael had to deal with situations involving intimacies which were “peculiarly private” (Parsons, 1951, p. 451). This objectivity was important, because it legitimised

Michael's access to the woman's breast, and involved a high level of trust by her in him as the professional.

### **The Medical Subjectivities and Identities of the Woman Undergoing Treatment**

The process of cancer treatment began for all of the women and the health professionals with the metaphorical 'fight for life'. The generally-accepted intention of medicine and public health is that health and life are to be fought for and saved by medical intervention. As such, the metaphorical conceptualisation of the war against disease is, in the eyes of the medical establishment an appropriate one. Medical discourse commonly includes martial expressions like "... the vanguard of medical science..." where "...the important thing is to win...", or to achieve a cure which is the "...long-promised victory..." (Guggenbühl-Craig, 1980, p. 7).

To a greater or lesser extent, the women undergoing treatment for breast cancer were credited with, and assumed the subjectivity of 'fighter'. Beholden to medicine to treat them, they were charged by medical expectations to join with medicine's efforts and do all that they could to not succumb to the disease (Blaxter, 1983; Herzlich, 1973; Gwyn, 2002; Shilling, 2002; Williams, 2005). The response of some of the women to the crisis of breast cancer treatment called for an all-out effort to alter the course of their illness by changing who they were.

*The oncologist said that my body was "at war; invaded by an enemy". We had to fight it and win. I had to believe that I had very good prospects of getting through it, and I was going to try my hardest. I viewed the treatments as a challenge, battles to be fought and won. I absolutely had to believe that if I fought alongside the treatment I would survive.*

Rose

Rose and her oncologist's constructions of cancer were illustrative of contemporary accounts of the courageous aspects of undergoing treatment for breast cancer, and the struggle by patients and oncology against the disease. Rose was challenged by the idea of treatment but equally determined to survive. In the course of this study, participants used expressions such as:

*If it strikes you; being shell-shocked; get rid of it; breast cancer shows no mercy; breast cancer is an invading foe; the lump was a beacon signalling dangerous water ahead; the body puts a protective covering of tissue and fluid*

*around the foreign body; precautionary surgery; my war against; fight; struggle; cancer can be beaten; I'm a Can-Survivor.*

The media and popular press and medical articles routinely feature stories about heroic individuals who have 'battled' cancer by undergoing treatment and surviving. Rose's use of the military metaphor, and taking a fighting stand were apt because of the common constructions of an enemy (the cancer), a commander (the physician), a combatant (the patient), allies (the healthcare team), and formidable weaponry (including surgical, chemical, and nuclear weapons) (Reisfield & Wilson, 2004).

The medical use of martial and militaristic metaphors is not limited to health professionals and patients only. Pharmaceutical companies commonly use them in marketing their chemotherapeutic agents. An American example of a website advertising an aromatase (oestrogen inhibitor) which has become widely used in New Zealand implores women to "'Fight Hard and Fight Back' in your battle against advanced breast cancer" ([www.rx24.7.com/buy-femara-nz.html](http://www.rx24.7.com/buy-femara-nz.html), 2009). Another advertisement for a similar aromatase inhibitor described it as "early breast cancer's daily opponent" and features a breast cancer patient donning hot pink boxing gloves emblazoned with the trade name of the drug. Yet another features a woman wielding a sword, in this case a visual metaphor for liposomal doxorubicin (a drug sometimes used in the treatment of advanced breast cancer), and proclaiming that it "fights as hard as she does". The front and back sides of an information booklet about Arimidex (the aromatase inhibitor anastrozole, used to treat breast cancer after surgery, and for metastases in both pre- and post-menopausal women), displays a woman wearing boxing gloves standing proudly and victoriously with gloves aloft in front of the metaphorical punching-bag (breast cancer).

A woman who dies is commonly described as 'losing her battle with cancer', and those who do not die are seen to have engaged in and won a heroic fight against the disease in the tradition of the archetypical hero (Penson et al., 2004; Reisfield & Wilson, 2004). Rose presented a fighting spirit in her active efforts to overcome the adversity posed by the diagnosis of breast cancer. This represented her dogged preparedness to fight for her life, regain her strength and remain fully involved in the process of living. The subjectivity of Rose as the heroic battler was a powerful metaphor for the predicament of those women who put all trust in their invasive treatment regimes, most of which were determined by remotely situated oncologists. Reinforced in the public mind, a state



of war was a prevalent allegorical model which emerged in the participants' accounts, and the discursive object of the 'enemy' was to be feared.

In contrast to the women in this study who assumed the identity or were recognised by others as having a fighting spirit, some of the women experienced a loss of identity because they were so dominated and overwhelmed by medical practices. Some of them facing surgery, for example, experienced significant issues relating to loss of identity as a result of the anonymity and loss of control in the process (Collins, 1994).

*I felt like just a number in the surgical ward, on a conveyor belt type of thing.  
You are just a number in the system.*

Jessie

*In the ante-room before they give you the anaesthetic we were just bodies on  
trolleys, all gowned and booted, lined up and ready to go.*

Nancy

*In and out in seven minutes, wham, bam, like, see you tomorrow, same place,  
same time, same laser beam*

Carol

Jessie was reduced to feeling she was merely a number, another anonymous hospital statistic. All of the women were constructed similarly as small nameless but numbered components within a large medical system. A different but aligned Foucauldian technique of power (as in the concepts of bio-power (Foucault, 1984), governmentality (Foucault, 1991), and 'trust law' (Hindess, 1996; Luhmann, 1979; Trados, 1998), was seen in Nancy's feelings of loss of control in her need to trust busy and objective others. Carol's experiences of radiotherapy revealed the anonymity and uniformity of the treatment process for her. Nevertheless, the need to undergo this type of treatment brought with it very different types of medical identification. Two of the strongest forms of the visual or physical classification of these women were firstly, their own self-identification, and then their identification by others, by means of the visual medical tattoo (skin markings for accurate radiotherapy dosimetry). However, for some of the women, the latter identification brought with it opportunities for camaraderie within the medical system (Lugton, 2002).

*I never thought that treatment for breast cancer could involve any further body  
scarring than surgery. Then I was tattooed. Tattooing always seemed to me to*

*be a voluntary form of body art, but this was not voluntary. In my mind the radiotherapy tattoos are clearly visible and make me a marked woman.*

Carol

*There was a sense that none of us were the same, but also that we were all the same – tattooed women. The radiation treatment is like a military line-up. The women are all in the same white hospital gowns and we sat rigidly along a wall.*

Carol

*Even though we were all terrified I'm sure, there was a sense of camaraderie. We were a sisterhood, a club, with our own freshly-laundered, logo'ed spotless uniform, worn the same way, at the same time, every day. We belonged to the XX Hospital. In the few minutes we had together we talked to each other. We were from all walks of life - wealthy scared women, whose money was no guarantee of buying back their health, - and women from more straightened circumstances. We were all in the position of having to trust the specialists to beat our disease for us.*

Stephanie

Carol talked about feeling that she had been identified by outsiders as a breast cancer patient by her radiotherapy tattoo. She re-emphasised the point that more medically-induced bodily scarring after surgery was involuntary. Her experience can be seen as the application of a medical technique of power, in that in order to receive accurate treatment doses she had to submit to another type of medical gaze and apparatus – one which left her indelibly marked, but one which was constructed by medical discourse as a practical medical rationality, governed by the conscious aim of treating cancerous tissue.

Stephanie's account showed that the radiotherapy unit located in a large hospital was the first medical setting in which she had physical proximity to other patients, all women. It was with these women that she aligned and identified herself in a collective subjectivity of comradeship (another type of battle metaphor), or sisterhood (a gendered construction), and upon whose group membership she drew strength (Lugton, 2002). The medical construction of her subject position – 'identification as patient', (Frank, 1991) signalled a significant need, and her fears were somewhat allayed by identifying with others in the same position.

### **The Discursive Practices of the Woman Undergoing Treatment for Breast Cancer**

The identification of the woman in this study, expected by medicine and society to undergo treatment and overcome breast cancer, was commonly demonstrated by her actions in ‘fighting back’. All of the women in this study were active during the treatment process, committing to a treatment plan and being able to see it through. Conversely however, medicine and society’s use of metaphors added to some of the women feeling burdened by expectations. Attempting to adopt a heroic stance brought feelings of guilt and a perceived sense of failure.

*There were times during the chemo that I felt like giving up. It was tough, almost too tough. I felt guilty and upset that I wasn’t going to be strong enough to make it and that I was letting everybody down.*

Diane

Diane showed her belief that expressions of despair or defeat were not easily tolerated by others, shown in her feelings of guilt. She revealed an anxiety that underlay the mental pressure on her to be heroic and positive at all times, when physically she could not be.

### **The Medical Identities, Subjectivities and Discursive Practices of Treatment Providers**

The specialist providing treatment for breast cancer is part of a large oncology team. Each member of the team has his or her own particular identity and role or persona, but all have a shared focus on the management of the cancerous tumour and the containment of cancerous cells (Blazeby et al., 2006). In this study, the scientific medical discourse constructed each professional as the expert ‘knower’ within the specialism of oncology, each with their objective gaze on the woman with cancerous tissue in her breast. Various, the medical techniques of power within the discipline of oncology created subject positions and subjectivities which invested the professionals with the responsibility of administering treatment. These included anaesthetising, conducting surgery, administering radiotherapy, infusing chemotherapy, and attending to the women’s physical and emotional after-math. The experiences of the highly contextualised settings for these treatments converged to produce subjectivities and practices which were challenging for the professionals. In the following section I analyse their accounts from within the medical discursive constructions of the three main types of treatments which were administered to the women.

The role of the surgeon, well-recognised as that of the skilled practitioner, has a long history in the medical discourse and practices of treatment for breast cancer (Mukherjee, 2010; Olson, 2002). Surgeons are trained and disciplined to objectify the body and the body parts on which they operate. Their objectification of women's bodies (Foucault, 1977a, 1978), were well exemplified in the accounts of two of the breast surgeons in this study.

*In surgery, we are focussed solely on the removal of the cancerous tumour. Some surgeries and reconstructions allow for the restoring of the natural contour of the breast, but essentially we do not get involved emotionally with the parts of the body we are operating on.*

Rafi, Breast Surgeon

*We all mean well with the treatments. The treatments are effective, but, I concede, very invasive. We don't just go around doing harm to women. It is difficult on an emotional level to amputate a woman's breast, and administering radio and chemo can't be much fun either. We can't get emotionally involved. We just have to think in a matter-of-fact way.*

Michael, Breast Surgeon

The identity and role of the surgeon, tightly disciplined by the protocols by which they must practise, were well illustrated by Rafi and Michael. They were positioned closely to the discursive object of a cancerous tumour in their patient's breast, and they were determined in the sole purpose of excising that tumour. Williams (2005) described this medical response as a type of "sentiment towards injury of the body" (p. 451). Both surgeons provided clear examples of surgeons' belief in surgery's potential to treat breast cancer effectively, and in themselves as disciplined practitioners through their real attempts to be objective. A practice of detachment was legitimated here, constructed as necessary, and as a way of coping.

All of the health professionals in this study, like the women, held firm to their hopes of oncology to effectively treat breast cancer.

*Even in the worst case scenarios I have to remind myself that there is always hope. Just because Mrs X died doesn't mean that Miss Y will, even with the presence of metastases. Every breast cancer patient should be approached with the hope of curability. But no cancer is treated so well that we could not do better. We can confidently expect continuing advances. This is the hope for*

*patient and doctor alike. Part of the oncologist's job is to show the patient that there are brighter things ahead. That's what makes the holding to some very nasty treatment procedures that much easier to justify.*

Geoff, Oncologist

Geoff, in his specialist role of oncologist, had the most detailed information about the natural history of the disease and its likely course and prognosis in a given patient. From this power/knowledge (Foucault, 1980), he generated treatment plans. Because of the authoritarian stance of medicine, it was most natural for him to assume an intellectual and leadership approach, for which medical training and practices had already pre-selected him.

Having the ultimate responsibility for decisions enhanced Rafi, Michael and Geoff's commitment to treating their patients, and their comments demonstrated their ability to maintain dedication and energy in the face of all outcomes. But their accounts also showed the underlying stress on them as professionals working in the field of breast cancer treatment, and revealed some of the strategies they used to keep themselves objective and safe. Traditional medical history shows that public perception of the health profession has undergone major shifts over the past fifty years (Armstrong, 1983). After World War Two, the health professional began to be viewed as the idealised treatment provider, knowledgeable in up-to-date scientific methods, and driven by the sole purpose of curing illness and disease (Morales, 1998; Mukherjee, 2010; Olson, 2002). However, modern science methods are popularly seen as not meeting, albeit unreal, hopes of prolonging life in some cancer cases (Mukherjee, 2010). Health professionals instead have opportunities to manage patient physical and emotional pain and suffering, which is sometimes prolonged because of the protracted nature of recovery from breast cancer (Holland & Weiss, 2010). (I expand on the construction and practices of protracted recovery in Chapter Nine).

Some of the health professionals in this study often found themselves in stressful situations related to the provision of treatment to breast cancer patients, and over which, like some of the women being administered them, felt they had little control.

*Feelings of guilt about aggressive treatments like chemotherapy can arise for GPs, but are often not readily admitted.*

Tony, GP

*Working with women with breast cancer is working in situations of ever-present emotional tension and every encounter has the potential for anguish, both inwardly and outwardly. I know that there are issues of burnout and clinically significant anxiety and depression in some oncology staff, particularly in those responsible for direct patient care like we nurses. Practitioners need more help with especially upsetting cases.*

Judy, Breast Cancer Care Nurse

*The loss of patients through failure of treatment is especially difficult for practitioners to deal with.*

Clare, Psycho-oncologist

*Sometimes I feel out of my depth nursing women with breast cancer. I'm what I consider to be a general nurse, and so sometimes I feel upset and inadequate that I don't know enough about the emotional factors about breast cancer. I don't quite know the right things to say to them.*

Kerry, General Practice Nurse

Tony's comment reflected his anxiety, constructed by him as guilt over the effects of the particular treatment of chemotherapy on his patients. The management of ever-present side-effects was a constant reminder to him of the cytotoxic nature of pharmaceutical treatments. For breast cancer patients these are mostly transient or cosmetic, such as nausea and vomiting, and hair loss, but they were also distressing for the professionals in this study because they were so difficult for some of their patients to endure. Some of the professionals felt anxious about iatrogenic complications induced by a treatment itself, and about disfigurement as the result of surgery. Less obvious effects such as the impact of breast surgery, radiotherapy, and chemotherapy on a patient's ability to conceive a child, breast-feed, and sexually-related problems (E. Adams, 2007; Hawkins et al., 2009) had a significant emotional impact on them, especially female nurses Judy and Kerry. Few physicians deal with death and grieving as often as oncologists (Whippen et al., 2004), as indicated in psycho-oncologist Clare's comment. Such sentiments were echoed by some of the health professionals in this study.

### **Medical Techniques of Power in Treatment**

Nowhere perhaps, in the four stages of the breast cancer experience, as I have defined them in this study, was the Foucauldian notion of medical techniques of power, especially bio-power or the power over life, so well demonstrated as in the strategies of

treatment. The medical management and control of cancer was firmly placed within the discipline of oncology. In order to eliminate the cancerous tumour from the body, the woman, in the first instance, was rendered unconscious by anaesthetic. It could be argued that there is no greater medical power than having the ability, technological means, and consent to make another party senseless, and thus to become totally dependent on others.

### **The Effects of Medical Techniques of Power on the Woman Undergoing Treatment**

Anxiety and fear were commonly experienced by most of the women within the power relationships inherent in their treatments in general. In addition to confrontation with, and adaptation to loss or possible death, and anxiety about body image during and after treatment, for some there were other fears. These involved anxiety about being alone in unfamiliar clinical environments, fear of losing control by being anaesthetised, the experience of radiotherapy and/or the effects of chemotherapy, and of dying during the operation.

*I really disliked the idea of being rendered unconscious by anaesthesia. I had to trust the anaesthetist. I could only go forward into the unknown.*

Christine

*It might be easy for hospital staff to forget how unfamiliar almost everything connected with a hospital admission and stay is.*

Jessie

The other two main treatments for breast cancer, radiotherapy and chemotherapy, while not requiring anaesthetic and loss of consciousness, created further spaces for the emergence of the dependent patient. Such critical dependency exemplified the Foucauldian notion of the power which was played out in the relationships between a health professional and the woman (Lupton, 1997). For Christine and Jessie the hospital environment and practices were strange, frightening and unsettling. Enforced engagements with sets of unfamiliar medical specialists, the institutions of breast cancer treatment such as the breast clinic, operating theatre, radiotherapy unit or chemotherapy ward, and the technology of treatment procedures, created anxiety and confusion in most of the women. Christine and Jessie were examples of all of them who knew they must undergo treatment in order for their lives to be saved, but who found themselves as strangers in the life-saving territories of powerful others.

Deconstruction of the discursive interactions between the women and their treatment providers revealed both disempowering and affirming constructions and practices. Medical management of the women during the first few days or weeks following their confirmed diagnosis usually included discussions about disease status, prognosis and the development of a treatment plan. The primary treatment consultation was of particular importance to the women because that was when their specialists outlined treatment options, and the women could, ideally, make informed treatment decisions (Auerbach, 2006). However, some of the women experienced primary treatment consultations characterised by too high a degree of the biomedical information given by their oncologist or surgeon.

*I would have preferred a few choice words rather than what seemed like a lengthy medical lecture lacking meaning. Women are becoming increasingly aware of the options, mostly about full and partial mastectomies and reconstructions. We want to be heard, and doctors need to give more time to hear us.*

Jan

Jan's experience was probably not surprising, given the complexity of the disease trajectory and treatment regimes that were likely to have been discussed during her consultation. But she alluded to the relatively small amount of discussion time dedicated by her specialist to her emotional response, or to the checking of her understanding. She talked about an underlying anxiety stemming from her need to be communicated with, rather than dominated by, medical discourse.

A further technology of medical power was seen in the multi-disciplinary professionals-only conference to decide treatment.

*My surgeon said, "We talk about you behind your back, we decide what we're going to do, and then we tell you".*

Jessie

From a medical point of view, this discursive practice represented a well-developed and effective approach to patient care, and reliable co-operation between various 'experts' (Blazeby et al., 2006), but created difficulties for Jessie, who did not feel involved in the decision-making about her (Auerbach, 2006). The growth of the medical consumer movement has resulted in more demanding, more knowledgeable patients who expect to play an active role in any decision-making about them (Moloney & Paul, 1991; Morgan,



2003). For women, questions around breast cancer treatment are possibly more multiple and complex than any other disease because they include both surgical and technological aspects and multiple issues related to feminine subjectivity. These can include the nipple, mastectomy, lumpectomy, breast reconstruction, womb, scars, prostheses, clothes, sterility, hereditary factors, prognosis, causes, general health, sex life, wellness, deformity, recovery and return to former self (Holland & Weiss, 2010).

Jessie's comment showed her doctors to be in the position of possessing more knowledge about a part of her body than she had herself. As such, they also possessed greater power in terms of the manner in which, and how much, knowledge was to be divulged to her, and about their treatment decisions – indeed Foucault's (1980) power/knowledge, and power over life (Foucault, 1984). Such distancing of professional from patient, as recounted by Jessie, was sometimes worsened by the fact that most of the women were informed about their treatment by a different professional from the one who had given them the diagnosis (Salander, 2002).

#### **The Effects of the Medical Techniques of Power on the Professional Treatment Providers**

For all of the women undergoing treatment, there were significant ramifications which were alleviated or worsened by the quality of their interactions with their treatment providers. But some of the health professionals too, were affected by certain features of this clinical and social interface. Changes in the doctor-patient relationship over recent decades (Lupton, 1994b; 1997) have significantly altered the breast cancer treatment decision-making process (Auerbach, 2006). As seen in the imparting of the diagnosis, described in Chapter Seven, some of the doctors in this study again constructed some of their patients as “difficult”.

*Women are either very quiet and accepting, or very emotional, which is understandable. Some can be very difficult - demanding and challenging when it comes to talking about treatment. Our training is very technologically-orientated and only goes part way, if that, to preparing us for these difficult encounters. I have very few opportunities or time to talk face-to-face with colleagues about patients' various reactions to treatments.*

Ross, Oncologist

Such discursive practices were underpinned by Ross's assumption of a position of power and authority in his doctor-patient interactions. He cited his technological expertise as the reason for avoiding testing interactions. Although he was aware that his

patients were likely to experience emotions and demonstrate behaviours which would create tension, he viewed these as interfering with his ability to provide effective medical care. As such, his patients' behaviour evoked such negative feelings in him that he constructed their subjectivity as "difficult", itself a pejorative and emotionally-charged label.

The 'difficult patient' is a common medical construction (Haas et al., 2005), and a term which has been recognised in empirical medical discourse since the 1970s (Walker et al., 1990). Ross's patients' accounts of their experiences contributed to his awareness of his patients' fears about treatment. Medical discourse generally constructs the treatment provider as an essential and ubiquitous partner, in whom patients have no option but to trust (Goodyear-Smith & Buetow, 2001; Little et al., 1999). As a result of this powerful position, the stress associated with the nature of the doctor-patient relationship was high for Ross, exacerbated by the unavailability of supervisory or supportive discussion with other professionals. Confrontation with the possible death of some of their patients, and common exposure to women's disfigurement, was therefore a permanent subtext which could not be fully explored by some of the doctors in this study. Tony gave a reason for this.

*The grief-stricken professional is publicly unacceptable.*

Tony, GP

Tony was maintaining the front expected of professionals, but both his and Ross's comments revealed that they had not been taught, or were ignorant of the skills needed to deal with the emotions of their patients. Tony's comment also showed that the toll on health professionals working in the area of cancer can be hidden and unaddressed (Whippen et al., 2004).

The emotional toll on breast cancer patients was addressed for some of the women through mechanisms such as dialogue with their professionals and support groups. This was not the case however, for all of them.

*There was no opportunity or possibility of a female-to-female chat. I would have welcomed that. As I said ... sheep through a dip.*

Carol

The time and resource pressures of the current, seemingly overpowering medical technology of breast cancer, were constructions within the bio-medical model and of

bio-politics (Foucault, 1976, 1984), with associated discursive practices interpreted by Carol as negatively influencing the medical system's ability to enter her (the patient's) world, and to see the disease and impact of the treatment from her perspective. With its general purpose of saving a specific population of women from breast cancer, the practice of bio-politics overlooked the individual side of treatment for Carol. The discursive practice of professionals not seeing more time spent with patients as valuable, could be deconstructed as having constrained such opportunities for her. Other professionals in this study however, were aware of some of the emotional aspects for their patients undergoing treatment for breast cancer.

*In all of my interactions with patients when things are serious, such as with a breast cancer diagnosis and treatment, I can see that there is a lot going on for the patient that I can't get to.*

Kerry, Practice Nurse

*Rather than just a medical GP, I now find myself as an explainer, a manager and a motivator. I start with the patient's knowledge and experience about breast cancer and work from there rather than pushing my own clinical perspective. Doctors need to be aware of a number of interacting medical, emotional and social issues.*

Veronica, GP

Both Kerry and Veronica indicated that the medical technologies inherent in the diagnosis and treatment of breast cancer had necessitated a change or addition to their roles as primary health practitioners. Over the past fifteen years there has been a turn of the medical gaze to the 'whole' patient (Cella, 2001; Holland & Weiss, 2010; Miller, 2010). In today's medical world this is acknowledged as a relatively new phenomenon. Even as recently as the late-1990s, statements were found in manuals and courses for training medical staff in communication skills such as "With its foundations in sociology and psychology, the patient-centred approach is sometimes as foreign to physicians as biomedicine is to patients" (Roter & Fallowfield, 1998, p. 1074). Some of the professionals in this study had made great efforts to embrace the new practices of health care.

*I try to understand the patient as a unique human being. It is easier with those who have been my patient for a long time because I know quite a bit about*

*their personal lives, and can gauge a little about how and where this will all impact most.*

Tony, GP

*I try to see the situation from her perspective rather than solely from a doctor's point of view, because I know that there are a number of interacting physical, emotional and practical issues which can impact on the situation. But we need both types of relationships, otherwise medicine wouldn't work. The objective medical stance is necessary in certain situations, such as breast or other intimate examinations, surgical interventions, radio and chemo, or other stressful medical moments.*

Rafi, Breast Surgeon

Tony and Rafi were illustrative of some of the breast cancer treatment providers interviewed for this study who had made, or were making, a conscious shift to a more holistic approach to their patients. Rafi's expressed need showed clearly the dilemmas of his subject positioning and identity as a professional. As with the imparting of a confirmed diagnosis, his provision of treatment for breast cancer called equally for him to be a subjective comforter and an objective expert. As he acknowledged, there needed to be a two-way partnership in order to allow him the co-construction of the subjective meaning of his patients' illnesses. Tony and Rafi's comments reflected the power of common good in the quality of the doctor-patient relationship. As Foucault (1984) emphasised, any power relationship has the potential to be a necessary, productive and positive force. One area of interactive asymmetry in which discursive demarcations are relatively clear-cut however, is the point where gender and treatment for breast cancer meet (Fisher, 1995). It is the gendered discursive constructions of breast cancer treatment which I explore in the next section of this chapter.

### **The Gender Discourse of Treatment**

It is part of the feminine ideal in Western cultures to have well-shaped breasts proportional to other parts of the female body (Connell, 2009). The sociocultural and gendered constructions of the female breast as womanly, female, full-bodied and sexual are well documented, and played a very important part in how the women in this study experienced and talked about their breast cancer treatment, particularly surgery (Malterud, 1999). For the woman and her treatment team, the female breast remained firmly under the medical gaze. However, the breast came again under close gender scrutiny. I argue in the following sections of this chapter, that strong emotional

responses from some of the women arose at the intersection of gendered and medical constructions of their treatments.

### **The Gender Discursive Object – The Endangered Breast**

The female breast's ability to produce milk means that it can feed, nourish and bond dependent young (Broad et al., 2006). Lactation is unique to the female mammal, 'mammary' being constructed in gender discourse and in most languages with acronyms and derivations such as *Ma*, *Mum*, *Mam*, *Mummy*, *Mom*, *Mommy*, *Mother*, *Mumma*, *Mammie*, *Yamma*, *Ima*, *Oma*, *Oleaa-sama*, *Mater*, and so on. Modern surgical treatment is much more conservative than earlier (Mukherjee, 2010; Olson, 2002), with every attempt now being made to save as much of the breast as possible, including the nipple. However, what cannot be denied, as revealed in the deconstruction of the accounts in this study, were the particularly gendered effects for the women significantly related to the specific site of surgery. The gendered discursive objects which emerged from the study participants' accounts were the female breast endangered by medical treatment, and by association, endangered femininity.

*Half a woman. As a woman you must be worth less if you lose a breast or even part of a breast. It means part of you as a woman has gone. You are deformed.*

Stephanie

*It is the feminine side they are operating on, taking away. Of course there are prostheses now, so we are probably alright and we all look like real women again, if only from the outside.*

Kim

Stephanie and Kim revealed their constructions of medical treatment as a threat to their feminine identity (Harding, 1997), personality and integrity. Stephanie's comment showed the emotional turmoil experienced by some of the women with relation to surgery to their breast, and more especially to mastectomy. Both women deployed the gender discourse that the female body was enhanced by appearance, and exposed the deeply gendered significance of the breast in relation to their identity as women. With a breast or both breasts removed by mastectomy, a self-identification emerged for them as 'less than woman' (Kristeva, 1982) – a degradation of their own bodies, and a place of social exile or abjection.

## **The Gendered Subject Position of the Woman Receiving Treatment in 21<sup>st</sup> Century New Zealand**

Language and gender research emphasise performative approaches to gender (Butler, 1990; Connell, 2009; Kimmel, 2000). From the analysis of the women's accounts, two main subject positions and roles emerged – (1) the woman and her body image, and (2) her social roles as sexual partner and mother. The history of breast cancer shows that since time immemorial, breasts have been constructed as one of a woman's most prized physical attributes. They have been portrayed in sculpture and paintings, representing the visible signs of female sexuality and eternal feminine beauty (Olson, 2002). For most women in Western society, the breasts are constructed, to a greater or lesser extent, as representing a part of their conscious and unconscious gendered images of themselves and body-egos.

When applied to health and the experience of illness, the term 'embodiment' (Merleau-Ponty, 1945) has been used in a Foucauldian approach by Eckermann (1997) to mean the process or state of living in a healthy or unhealthy body. Eckermann also meant the gendered ways in which people understand themselves through their gendered constructions of their own bodies and their lived bodily experiences. My discursive analyses of the experiences of the women in this study showed that the gendered construction of the threatened female breast was brought to the fore by medicine's invasive treatment regimes. Oncology's concentrated gaze on the clinical object of the tumour in the breast, and the containment of invasive cancerous cells by objective treatment providers, impacted significantly, my findings show, I believe, on the body image and embodiment of most of the women participants.

*I was always very proud of my breasts. They were important to how I saw myself as a woman, partner, mother, my whole self-image. As girls we stuffed tennis balls in our jerseys to look like breasts. It was funny at the time. It wasn't so funny after the mastectomy and getting the prosthesis fitted.*

Mimi

Mimi's comment revealed the extent to which her breasts gave her satisfaction and contributed to her positive self-esteem prior to surgery. Her sense of pride in her body image, and the foundations of her feminine identity were firmly anchored in her breasts. Her reference to the girl-hood fun of enhancing the pubescent chest indicated the depth of her femininity (Walkerline, 1990), now rendered somewhat abnormal by surgery. In

order to be normalised (Foucault, 1977a) through a normalising gaze, Mimi chose to be fitted with a bodily profile-augmenting prosthesis.

The second key area in which treatment for cancer of the breast impacted most on the women was in the gendered, context-responsive arena of sexual activity (Eckert & McConnell-Ginet, 2003; Mills, 2008). Once private and special, the treated breast became much more public and open under an intimate gendered gaze. Those women in sexual relationships who were undergoing, and/or who continued to receive treatment, were in the gendered position and expected role of sexual partner (Baxter, 2003). Their treatment for breast cancer suddenly constructed their breast as problematic and impaired in its ability to perform expected gendered acts within the social roles of sexual partner and/or mother.

*There's so much talk about sex. It's always the breasts. And the mastectomy affects me in the sexual part. After all, a man reacts to what he sees. And he is put off by what he sees. It has the opposite effect. Other people live with missing limbs. People still function. Society thinks of them as handicapped, disabled, not able bodied. Well my breasts are not able bodied anymore either. I am angry because it is so difficult to accept that I am not as acceptable to my lover anymore. I might have been able to accept this possibility rationally, but not emotionally. The bottom line is, he is revolted by me, and I am revolted by me.*

Stephanie

*Women's breasts are erotically sensitive and important in sexual connections. Perhaps more importantly, the breast has always been a symbol of motherhood. When women are faced with any risk to their breasts, such as surgery for cancer, some regard it not only as a physical danger, but also as a danger to their ability to perform certain distinctly female acts.*

Richard, Psycho-oncologist

The loss of the breast signified the loss of an organ intimately associated for most of the women with their sexuality, femininity and self-esteem. For Stephanie, the mastectomy brought physical disfigurement and enduring body image issues, which in turn she blamed for the cause of her unsatisfying or negative sexual experiences. The disfigurement caused by lumpectomy, mastectomy or mastectomy with immediate reconstruction visibly embodies the psychosexually-charged trauma of being treated for

breast cancer (Campbell, 2009; Holland & Lewis, 2000). Stephanie was angered and anxious that the management of the dominating tumour was causing her such anguish. She was revolted by the thought that her breasts were no longer perfect, and that her sexual attraction and functioning were impaired by the surgeon's scalpel. Her treatment had caused her a sense of repulsion – that she was revolting to herself and others.

Richard, the psycho-oncologist, clearly articulated his location of the subject position of such women at the intersection of the medicalised and gendered constructions of the effects of treatment. As he pointed out, no matter what point in a woman's life treatment for breast cancer occurred, the gender discourse constructed her firstly as feminine. The identities and subjectivities of woman, wife, partner, mother etc. were significantly subsumed under the medical discourse, which consistently constructed her as a medical patient and a recipient of medical treatment. Because mastectomy was for so long the standard treatment for breast cancer, and still continues to be recommended for large numbers of women, Richard's observation revealed the significant impact of the loss of one or both breasts on women's physical, social and emotional functioning. The list for the women was long - mutilation, altered body image, diminished self-worth, loss of sense of femininity, decrease in sexual attractiveness, impaired maternal function, feelings of threat, and anxiety. These feelings were well encapsulated in Stephanie's account, and reinforced in Richard's general observations of women undergoing lumpectomy or mastectomy in general.

#### **The Gendered Subjectivity and Discursive Practices of the Heroine Undergoing Treatment for Breast Cancer**

In the women's accounts of undergoing treatment, and those of the professionals, the gendered subjectivity of the heroine emerged. She was the woman who was prepared to face adversity head-on, and who was determined to overcome the trials of treatment and its after-effects. The heroine was a common identity deployed by many of the women themselves, and bestowed on them by others, especially by some of the medical practitioners on their patients.

*My doctor said that I was a real battler – a very brave woman. I was determined to fight back. I saw the chemotherapy as my weapon against cancer. It wasn't easy. I was very ill, and at times I felt as if I was fighting to the death. Thoughts about my family kept me to it.*

Agnes



As described in Chapter Five, heroine myths have taken various forms, and an historic but familiar recurrence is that of the warrior queen or female martyr who is subjected to a series of trials of treatment and physical and emotional suffering. Such gendered subjectivities, as deployed and practised (Cameron, 2001; Cameron & Kulick, 2003) by Agnes, illustrated the enduring construction of the metaphorical fight against cancer – the persistent battle metaphor (Lerner, 2001; Penson et al., 2004; Reisfield & Wilson, 2004; Sontag, 1978). Agnes' determination to fight back dramatically fulfilled the criteria for archetypal heroism, and such determination also highlighted a number of benefits for her in her heroic stance towards cancer. The heroic urge is, according to Becker (1973), our most common defence against death. The deploying of a heroic stance by Agnes, while she was undergoing chemotherapy treatment, provided her some security, and a sense of identity and way to endure hardship and an uncertain future.

Agnes was urged on by her GP. It was a discursive practice countering the sense of loss of control and agency that typically characterises the experience of the docile cancer patient receiving treatment who falls back on hope for its effectiveness (Freundlieb, 1994; Holland & Lewis, 2000). Agnes revealed the importance to her of dealing with her illness and possible demise in an exemplary way, that is, with fortitude and dignity. The gendered discourse of heroism helped to focus some of the women like Agnes in setting priorities for action. All of the women who were interviewed for this study were poignant examples, commonly described in popular media, of 'the woman next door' who 'battles on' through punishing treatment regimes. Through courage and virtue these women were variously constructed as mythical heroines, expected by their health professionals, partners and families to undergo their treatments, come to terms with their bodily transformations, and to pick up their gendered roles of sexual partners and/or mothers.

Agnes's account however, also revealed that there was another discursive influence on her identity. Positioned at the intersection of the medical and gender discourses, she was part of a medical discourse which produced a compliant, docile female patient whom medicine expected to treat with minimal fuss and bother (McNay, 2000). There were heavy demands on Agnes to behave without reproach in the eyes of the professionals who treated her. This was compounded by the expectations she put on herself to get on through the treatment for the sake of her family. In combination, the medical and gender discourses produced significant emotional effects of responsibility and obligation (Lupton, 1994a; Shaver & Drown, 1986) for many of the women in this study.

## Summary

In this chapter I have identified and analysed the dominant discourses by which the women participants constructed the experience of undergoing treatment for breast cancer. Similarly I analysed the discourses deployed by some health professionals whose role it was to plan and provide this type of treatment. Not surprisingly, given the nature of treatment, the medical discourse was the most dominant. The three main treatments – surgery, radiotherapy and chemotherapy, involved very different medical approaches to the women's bodies and bodily systems. The particular nature of each treatment mode created a unique space for its discursive representation by the women who underwent it, and for the professionals who administered treatment and care.

The discursive analysis presented in this chapter identified two dominant discourses by which the women and the health professionals constructed treatments for breast cancer – the medical discourse and the gender discourse. These two discourses merged to construct the woman patient undergoing treatment as a female subject, but one still very medicalised. The interplay of the two discourses produced varying degrees of anxiety in both the women and the health professionals during the treatment stage of the breast cancer experience.

In the first instance the medical discursive object was cancer, with its biological cellular nature, and risk of further invasion and spread throughout the body. The key medically-constructed roles and speaking positions were those of the woman dominated by breast cancer and undergoing treatment, and the professional as treatment planner and provider. The woman's position was primarily as a medical patient, and the recipient of medical treatment. The process of administering treatment for breast cancer involved an array of specialist gazes, all with different professional personae as expert knowers in the fields of surgery, radiotherapy, chemotherapy or breast care nursing. Each brought to the medical setting an objective focus on the containment and management of the cancerous tumour and cells.

Treatment for breast cancer was in itself a discursive practice, or a variety of practices, but all of the medical practitioners had the shared motive of ridding the patient's body of cancer. 'For her own good' (Ehrenreich & English, 2005), the woman was passed from one specialist to another, each of them (or both of them) in different medical settings. The most potent medical technique of power operated at the level of anaesthetising the patient, rendering her unconscious and completely dependent on

others. Other complex oncological techniques of power, (but not as intrusive as surgery) operated on the women. These were the additional methods of treatment, to which they all submitted.

The gender discourse constructed the discursive objects as the endangered breast and endangered femininity. From a Foucauldian perspective, the breast remained the medical object, but there were strong gendered meanings in the subject positions of the female as sexual partner and/or mother. Many of the women talked about feeling uncomfortable in having to bare their breasts to the medical gaze for treatment. For them, what was once private and special suddenly became public. A central gendered identity assumed by many of the women, and conferred on them by their health professionals, was that of the heroic woman. These 'brave' women constructed the treatment experience as fighting back.

The administration of treatment for breast cancer gave rise to mixed feelings of tension, guilt, hopefulness and uncertainty for some of the health professionals, and strong feelings of anxiety or fear in the women. The deconstruction of the accounts of the women presented in this chapter, revealed the tendency for them to bring to treatment situations previously-conceived frightened notions of how it would be ... and mostly their fears were realised. Medical and gendered constructions of difficult treatment regimens and settings predominated. The anxieties and fears, and the visual and sensual realities of physical deformity and scars were cited by them as an impediment to their primary social roles of sexual partner and mother. In general, the medical and gender discursive constructions of treatment for breast cancer insured that anxiety or fear, often profound, were very much alive for many of the women.

The myriad of professional and personal demands required of the health professionals as planners and providers of treatment combined to cause some of them considerable anxiety. These professionals talked about their unease in treating such an intimate part of the female anatomy. Their lists of other anxiety-provoking pressures on them were also long. These related to their responsibility for treatment decisions, the demands of complex technological and scientific techniques and computations, increasing patient expectations and assertiveness, medical, ethical and emotional ambiguities and controversies, and intense and repeated difficult emotional situations of patient distress.

The processes and procedures of treatment for breast cancer, and the relationships between the women and the professionals in this study were complicated enough, but

made even more so by the perceived differential power positions and personal attributes of each of the participants in these relationships. The accounts cited in this chapter showed that treatment as a discursive practice, and the technologies of medical and gendered power had the ultraistic goals of enhancing the best possible recovery from breast cancer as the professional and the women, separately and together, could muster.

In the next chapter I analyse the discursive field of what I termed *recovery* from breast cancer. The perspectives of the women and health professionals are explored.

## CHAPTER NINE: THE DISCURSIVE FIELD OF RECOVERY

### Introduction

This part of the study's findings focussed on the discursive meanings of the adjustment to and recovery from breast cancer over time. In this chapter I identify and analyse the dominant discourses deployed by the women participants and by the health professionals during what I have termed the *recovery* stage of the breast cancer experience. I used the term recovery because it encompassed both the women's and the health professionals' meanings. My intention was to emphasise that from a Foucauldian perspective, even the notion of recovery was a discursive construction of their experiences. By recovery, the women meant a return in a broad sense to their normal positions or states of health. For the health professionals, recovery, or rather, recovered, was based on the medical model to mean a disease-free entity. The women's notion of recovery however, was antithetical to medicine's approach. The gender and social contexts put additional stresses on the women, now considered by medicine to have 'had' breast cancer. Following on from the previous three chapters, which focussed on the discovery of symptoms, diagnosis, and treatment, this chapter draws the study to a point where in the next and final chapter the main findings are discussed, and implications considered.

It is essential I make clear that the focus of this chapter differs from the preceding three. The analysis of discourses presented here pertains to the longer-term recovery over a period of time, and not to the participants' recall of their immediate reactions at the time, or predictors of their reactions. The differentiation is critical because the reactions to breast cancer cited in the women's accounts were the immediate responses to the discovery of symptoms, diagnosis and treatment, whereas recovery took much longer. The practices of recovery involved alterations, regulations, adaptations, and bringing order to the women's lives by both the woman herself and the professional. The findings in this chapter relate to the woman's perspective of how she was health-wise and emotionally at the time of interview, and how health professionals saw women moving on from diagnosis and treatment. This process is generally constructed by medical discourse as the trajectory of recovery from breast cancer (Ganz et al., 2011). In this chapter I also use the word aftermath, which I differentiate in meaning from recovery to mean the repercussions, consequences and happenings in the participants' lives as a result of the total experience of breast cancer. (A personal aftermath for me, as

pointed out by one of my examiners, was the writing of this thesis. Then it became clear to me, that the aftermath of my experience had very different resonances from those of my recovery). The findings I present in this chapter however, indicate strongly that for some of the women in this study the process of recovery was long, indeed, never-ending.

The time limit I placed on the women's eligibility for participation in the study was over one year from the end of direct medical treatment, and no longer than five years on. This put the women in a type of cohort of recovery, but their individual places in the recovery stage at the time of interview enabled a wide capture of their experiences. While there were some significant similarities, all of the women were recovering in their own separate ways.

In this chapter I argue that while it was the medical discourse and the gender discourse upon which the women and the health professionals predominantly drew, there was a third influencing factor which emerged from the analyses of their accounts. Rather than a discourse, as defined by Foucault, I considered this to be a psychological or emotional dynamic or domain. This choice of terminology was my attempt to emphasise that, following Foucault (Hook, 2007), there was no discrete discourse that could be applied to this study that could accurately be called a, or the, psychological discourse. Discourse analysis is frequently applied to the many sub-branches of the discipline of psychology (Rose, 1985, 1996a), but from a Foucauldian discourse analytic perspective, the language within which one's experiences is framed is seen not simply as describing the emotional aspects of one's experiences of the world, but also as constructing them (Good, 1994). For Foucault, psychology was seen as a discipline that produced 'philosophies of events' (Hook, 2007).

Following the basic Foucauldian tenet, the object or phenomenon of breast cancer does not have its origins inside the individual. The concept of 'the individual' is itself a product of Western discursive practices (Kitzinger, 1992), and is constitutive of individuals as social products - for example, the breast cancer patient, the oncologist. When discourse analysis is applied to emotions and psychology, "instead of studying the mind as if it were outside language, we study the spoken and written texts ... where images of the mind are reproduced and transformed" (Burman & Parker, 1993, p.3). Discourses are productive, and in this way the discursive location of the individual frames his/her personal experiences of self and subjectivity.

The women's and the health professionals' subjectivities in this study were greatly shaped by the available discourses, practices and meanings of medicine and gender surrounding breast cancer. But attention to these discourses also informed the emotional or psychological aspects of their personal experiences of self and subjectivity, (particularly so for the women), in the context of their everyday emotional well-being during the recovery stage. Psychology was not seen then, as a specific discourse in this chapter, but as a significant extra-discursive state (Foucault, 1972, 1973, 1989; Hardy, 2010; Wilkinson & Kitzinger, 1995).

The analysis presented here involved the identification of the subjectivities of the speakers as they appeared during the recovery stage. The analysis also examined the influence of the techniques of power which emerged to either promote or hinder what the women and the professionals meant by recovery from breast cancer over time. I argue that the interplay of the medical and gender discourses produced both anxious women and anxious professionals.

### **The Medical Discourse of Recovery**

In discursive terms, 'recovery' has long been constructed in general medicine as both the process and the end of a particular experience or episode of illness (Holland, 2010). In this study, recovery was a discursive construct used in the medical discourse to define this particular period of time, and the point at which the woman was categorised by medicine to be free of the illness or disease. It was medicine's clinical view on how the woman recuperated and healed after treatment, medicine's management of further risk or relapse, and whether there could be a medical proclamation of a cure. Recovery in a broad sense has become a current matter of debate in medical theory and practice however, because there is now more awareness that it involves the perspectives of both professional and patient (Holland, 2010; Roter & Fallowfield, 1998; Stewart & Roter, 1989). In this study, the professional clinical view tended to focus on improvement in particular symptoms and functions, and on the role of treatments. The women's perspectives put more emphasis on the on-going physical and emotional remnants of treatment, vigilance about the recurrence of symptoms, and the regaining and retention of health and life-style.

### **Medicine's Discursive Object – The Treated Body**

Within the medical discourse, the discursive object of recovery from breast cancer was the body that had been treated. From a medical perspective, the tumour had been

eliminated, and the woman had been returned to her premorbid or more accurately, non-diseased state. Medicine had achieved its primary goal, but there was an overarching discourse. The current medical 'truth' that there is not yet a cure for cancer, meant that a body treated for breast cancer was not one that could be pronounced cured in any medically-guaranteed sense. For both the women and the professionals, there was continued potential for pathological danger (Miller et al., 2000).

*Breast cancer is a tricky business. While we have progressive treatments for cancer, we cannot depend on an absolute cure. Early detection and treatment are effective of course, but breast cancer is very unpredictable in the first instance, and more predictable in its recurrence. Most other cancers have symptoms directly related to life-style factors, but this is not so discernible with breast cancer. The incidents of women who get breast cancer twice, or even three times, or who develop cancer in the other breast from the first time, or even a different form of breast cancer in the same breast are concerning. Treatment does not mean a cure.*

Geoff, Oncologist

*Patients seem to recover well from treatment, especially surgery. This is probably because it is swift and clean-cut, so to speak - excuse the pun - whereas the effects of radiotherapy and chemotherapy can be on-going for long periods of time. We talk about radio- and chemo- as being "the gift that keeps on giving" because the effects are a longer-term attempt to prevent recurrence of cancerous cells.*

Rafi, Breast Surgeon

Geoff constructed the effecting of long term recovery from breast cancer as complex and risky. Society is dependent on medicine to treat cancer, but cannot depend on the delivery of a cure. Breast cancer is medically constructed as a disease which has to date largely outmanoeuvred medicine's ability to cure it, and the statistics of recurrence made the oncologists in this study uncomfortable. Rafi reflected a surgeon's pride in his work, but he also spoke of the on-going effects of the surgically-treated body and other systemic treatments. He constructed oncological treatments as a "gift" to his patients - a benevolent endowment from the discipline of medicine. But Rafi also emphasised the threat of the possibility of recurrence. Geoff and Rafi's gazes were firmly on the treated body. Both the surgeon and the oncologist focussed on the body recovering physically from treatment. Theirs was a biological notion, with an emphasis on the healing of the



physical wound caused by surgery, and the irradiated and chemically-infused body. In relation to the treated body, the woman continued to be positioned by medicine in the role of on-going patient; one who continued to experience and had to overcome the effects of treatment.

### **Subjectivities of the Health Professionals during their Patients' Recovery**

In this study, the impact on the health professions who dealt daily with the prolonging or saving the lives of their patients, was a subject not often considered by the women caught up in their own emotions about their breast cancer experience. My findings showed that issues relating to their patients mattered to most of the doctors privately as individuals, but that the women in general took their doctors' emotional resiliency for granted. The covert toll on the health professionals was voiced by some of them, but was, in my opinion, under-estimated and unrecognised by most of the women, who held strong expectations of their medical practitioners' upholding of values and the delivery of a professional service.

*I am actually always aware of the fear that women have of breast cancer, and I do struggle to convey the bad news when it happens. I seem to have to do it more and more these days, and there is a cumulative cost to me, I think.*

Tony, GP

*If we are not careful, always giving of ourselves can take its toll. Dealing with cancer patients every day, while vocationally rewarding, is also stressful. There is also stress caused by poor systems, time constraints, and poor communications and communicators. We have to find sensible ways of dealing with it and keeping ourselves safe. Doctors need strong relationships, and multidisciplinary approaches.*

Oliver, GP

*Until this interview I've never been asked by an outsider to talk in depth about my work. It has made me realise that it helps a lot to talk about what is expected of me, and the challenges I face both within the system and with my patients who are always upset and anxious about the effects of treatment.*

Rafi, Breast Surgeon

Tony, Oliver and Rafi were all empathetic practitioners who were struggling to transcend every-day adversity. Rafi's comments were important in highlighting the isolation experienced by the specialists in this study. Apart from medical conferences

and peer reviews, it would appear that there was little formalised emotional support for them. Dealing with the consequences of medical treatment for his patients became problematic for Rafi because the women displayed emotions which impacted on him.

Tony's comments reflected the vigilance of the health professional. He was cognisant that his patients were afraid, but he was also constantly struggling in his role as the conveyor of bad news (Fallowfield & Jenkins, 2004; Salander, 2002; Sweeny & Shepperd, 2009). This was because of the way the medical discourse constructed cancer – it threatened life and was disruptive. Deconstruction of his comments conveyed a potential problem in the doctor-patient relationship, as his resiliency was wearing thin.

Oliver's comment about his challenges of working within systems, and of time constraints, showed that he experienced conflict between his desire to participate more in his patients' lives and the demands on him of increasing corporatisation of medicine – shorter appointment times, more appointments in a day, the charging for all services and materials, and so on. Oliver's words constructed him as a front-line doctor, a driven professional who was in the position of having to face many potential failures in the course of his work.

Tony, Oliver and Rafi, two GPs and a breast surgeon, all talked about the stress and worry from their encounters as highly trained professionals with the messes and predicaments of their patients' real lives. It seemed to them that such disquiet was inevitable. Some of the health professionals were aware that they made distinctions between their practice and their experiences in their need to protect themselves from the emotions involved in the sensitive work they undertook daily.

*Sometimes I feel as if the conversation I'm going to have with a returning patient is a rehearsed, repetitive performance, somewhat robotic. I do worry that I might become inured to anguish and suffering, because as an oncologist, the dreaded 'Big C' is a huge part of my everyday life.*

Ross, Oncologist

Such on-going worries as revealed in Ross's self-reflective practice, were acknowledged in the words of June Goodfield, British scientist and writer of fiction and non-fiction, (1975, quoted in Mukherjee 2010, p. 11) who wrote "Cancer begins and ends with people. In the midst of scientific abstraction, it is sometimes possible to forget this one fact. ... Doctors treat diseases, but they also treat people, and this precondition

of their professional existence sometimes pulls them in two different directions at once”. Ross’s use of the word “inured” constructed the notion of immunity, a medical term in itself, and a desirable state of protection against disease for the patient. Conversely, as a medical practitioner, Ross was mindful of the potential for him to become accustomed and hardened to the undesirable circumstances of his patients. Foucault (1988) conceptualised this hardening as an ethical issue for those in positions of power. That is, ethical behaviour for a medical practitioner like Ross was the conduct required of him so that his actions were consistent with the moral code and standards of moral approval of the practice of medicine. Because some of the health professionals in this study experienced these feelings often, they became so much the norm that they were no longer distressed by the women’s reactions. Such discursive practices prevented them from acknowledging that each woman and her reactions were unique, so well described in the words of Jenny.

*I get many reports from patients who tell me about specialists who do not connect with them. Patients can see this and feel it clearly. Such unengaged medicine must be a lonely place.*

Jenny, Breast Care Nurse

Jenny’s account was illustrative of the anxiety and behavioural responses of some health professionals, fed-back to her in her role of breast care nurse. Her construction of this dis-connectedness between the two parties demonstrated the professional loneliness of some practitioners.

While the medical profession is resolute in treating breast cancer and monitoring patients’ progress afterwards, the subjectivities which emerged for the professionals in this study, in relation to their patients’ recovery from breast cancer, were varied. The ways in which the professionals viewed the behaviour of their patients at this stage were based on their understandings of the world upon which their own medical practice was based. Some of the professionals took an empathetic stance, and some were distant or dismissive.

*I recognise the many effects of having had breast cancer across patients’ lives – especially physical, energy levels, intimacy and self-esteem. We need to maintain positive relationships with our patients. We need to acknowledge their bravery, and also the bravery of those working in science and research.*

*Whatever happens, there will always be positive and negative times, winners and losers, so we all need to be more of a team.*

Tony, GP

*In my experience, it seems that most women who have had breast cancer see life differently afterwards. They re-assess their lives, and seem stronger somehow. Some have made some huge life-changing decisions as a consequence.*

Veronica, GP

Empathy has more recently been discursively constructed as an important, some would say essential, component of medical care. Empathy implies compassion, and the women in this study had come to expect that the medical practitioners with whom they came into contact would identify with them as people needing help, and that there would be some degree of acknowledgement of the difficulties they faced (Holland & Weiss, 2010). This assumed a sensitive and caring practitioner who demonstrated a feeling for what it was like to be on the other side of the consultation desk.

Tony was a professional who understood and was able to verbalise the whole gamut of the long-term effects of recovery from breast cancer by most of the women with whom he had been involved, and the strenuous effort required of them. But he also perpetuated the construction of the field of oncology as a contest with success and failure. As revealed in oncologist Geoff's earlier comment, Tony also recognised medicine's failure to date to affect a definite cure for breast cancer, and he voiced the need for medicine to better acknowledge the empathetic interdependence of doctor and patient in the whole breast cancer experience, including its potential aftermath. Veronica was an empathetic health professional who was able to recognise and respect a character-building nature of the breast cancer experience for her patients.

For the women in this study, the quality of the patient-physician relationship was extremely important in terms of how each party viewed the other. If cast negatively, there was potential for *on-going* distress or resentment between the woman and her doctor. This could last for some considerable time after the treatment itself had ended, and seemed to occur mostly on the occasions when the women and professionals met again in further medical consultations (Leopold, 2000; Little et al., 1999). Some of the women were aware that their doctors had viewed them as 'difficult'.

*My doctors seem to have an expectation that I should be over it, as if it is all over and done with, and there should be no on-going issues for me.*

It was not clear here whether Jan's construction of "it" is the discursive *phenomenon* of her breast cancer itself, or the *process* of her recovery from "it". Whatever the interpretation, she talked about how *all* of her doctors, not just one, had an expectation or an ideal about how she was supposed to behave. Her doctor-patient relationship was complicated by her unstated but implied on-going suffering and limited ability to relieve "it" on her own. Jan's account showed how the medical discourse and practices rigidly differentiated and separated the physiological processes of breast cancer from her on-going emotional and social recovery.

### **The Medical Subjectivities and Identities of the Woman Recovering from Breast Cancer**

One of the most common lasting impressions of having been treated for breast cancer recounted by the women was that of the dichotomy of their identity as cured or merely treated. This was probably the result, partly at least, of their knowledge of the high incidence rate of breast cancer recurrence and medicine's inability to guarantee a definite cure (Andersson et al., 1991; Botteri, 2010).

*I believe now that once you have been a cancer patient, you are always a cancer patient. The eternal cancer patient. You always have to keep an eye out for it because breast cancer can linger, and because of that, and, after all of this time, I am still not over the shock of those words "you have breast cancer". I really hope that it doesn't happen, but really, I wouldn't be surprised if I heard those words again sometime in the future.*

Carol

*I'm not sure whether I have or had breast cancer. I'm not sure where I fit. My life, which I took some-what for granted has been threatened, and I have become much more aware of my inner fears and fragility. I get very nervous before check-ups, mammograms or any other medical business.*

Nancy

The women in this study constantly faced the fear of recurrence, and this was compounded for some by their feelings of ambiguity about their cancer status. As Nancy showed, she was uncertain, and felt that she had little control over her fate. Some of the women struggled emotionally, years on, with an experience which was traumatising at the time they were going through it, but which also left a legacy of trepidation and alarm. There was no discernible end to the complications and

ramifications for these women. Their physical, social and sexual functioning was interwoven, with on-going emotional effects. As a result the health status of the women is psycho-socially constructed by some as a chronic rather than an acute condition (Baines, 1990; Cella, 2001; Tritter & Calnan, 2002).

Carol continued to assume the identity of the cancer patient, a strong identity which first emerged in the diagnosis stage and one which remained characteristic of how she constructed, and was constructed by the enduring medical discourse. The lasting nature of the impact of her sudden and unexpected change of health status from well woman to unhealthy patient was also seen in her inability to overcome the distress which the diagnosis of breast cancer shaped for her. Nancy talked about her experiences of vacillating subjectivities, as shown in her use of the conflicting tenses “have” or “had”. She was unsure where she fitted, and was unable to position herself firmly in any medical accuracy or truth. Both Nancy and Carol had their places in one medically-constructed group (the treated), but were not sure if they belonged in the other (the cured). Sontag’s (1978) construction of dual citizenship is exemplified well here in the women’s dichotomous medical position. Theirs was a lonely position, despite the camaraderie of other breast cancer women, and epitomised the practices of the ever-vigilant, ever-fearful woman (Altheide, 2002; Hollway & Jefferson, 2000).

### **Medical Techniques of Power in Recovery**

One of the most influential medical techniques of power was seen in the woman who continued to practise self-surveillance. Most participants in this study continued to keep a close watch on their breasts and bodies after their last treatment, and were compliant in self-examinations, and in undergoing continuing GP examinations, mammography and ultrasounds, and turning up regularly for specialist consultations. While remaining fearful, these women were those that medical and public health discourses constructed as ‘responsible’ - Foucault’s (1991) concept of governmentality at work.

*I continue to see the oncologist every three months for about seven minutes each consultation which I pay \$110.00 for. I have been told by him that I need to do this for five years. It seems an incredible amount of money, but I will see it through, because then I cannot reproach myself for not doing everything I could have, if the cancer comes back.*

Rose

*Even though I was told that the cancer had gone, every ache and pain now worries me. I now keep a very close watch on myself, and make sure that I have my annual mammography. Five years on, and I'm back on the yearly schedule, which is comforting in a small way. Sort of back to where I was.*

Stephanie

Both Rose and Stephanie were positioned by medical discourse as continually threatened women, subjugated and compelled into action by oncological and public health messages of recurrence of disease (Petersen & Lupton, 2000; Turner, 1997). Both women showed decisiveness, determination and accountability in trying to do all that they could to protect themselves. Stephanie paid the price by continuing to be worried, and Rose made a considerable financial investment. Their anxiety can be seen as two-fold – fear of recurrence of disease and fear of self-blame or fault. Because of this, both women felt obligated or morally bound to continue to practise self-care and self-surveillance. Medical surveillance continued strongly then, for these women in recovery. The treated body continued to be watched through on-going examinations and screenings. The women continued as patients under on-going scrutiny, and often with unexpected outcomes, such as eligibility for free influenza vaccinations, explained away as “because you have had cancer”, or “because your health is fragile”, and which perpetuated their medical status regardless of whether they felt well and effectively treated.

A further effect of a medical technique of power was seen in the subject position of the trusting and grateful patient. The resiliency of the women was demonstrated by their strong belief in their recovery, and in their reliance on and trust in their doctors to support them through. While not fully congruent with a Foucauldian historical analysis, the concept of the ‘trusting woman’ has stood the test of time. Women described in social histories and narratives of breast cancer turned to their physicians for the medical or surgical interventions of the time (Baum, 1986; Cantor, 1993; de Moulin, 1983; Morales, 1998; McCarthy, 2005; Mukherjee, 2010; Olson, 2002, 2009). The seeking of alternative treatments was a much more secondary discursive practice, and was not evident in the accounts of the women in this study. Trust in medical intervention continues to prevail, and was a recurring feature in the quality of the interactions between the women and the health professionals.

*The things that you don't forget are when the doctors wish you well and say that they want to cure you. I feel very small where things like this are*

*concerned. At such times one is not so proud. I trust what the doctors say, and that I will be saved.*

Nancy

*For long periods I almost forget all about it. Obviously you can't forget about it altogether because you have to undress and shower, dry yourself and that happens every-day ... but yes, in the end I have got to where I no longer react badly to my own reflection. To start with the re-construction looked so ghastly, but when the doctor said "this is looking really good" I felt a lot better about how I looked, and his words are what I cling to now, and he gave me strength, because I know that I could have ended up looking a lot worse.*

Judith

Nancy's extract showed her faith in her trust-worthy doctors. She was positioned, and positioned herself, as dependent, modest and humble. Nancy also showed the inherent power in the manner and content of what her health professionals conveyed to her, and how this impacted significantly on her self-perceptions of well-being.

After her surgeon's comment, Judith viewed her body in a more positive way. This was the direct result of the surgeon's expectations for cosmetic outcome (and reflected a touch of his pride in his work). From a medical perspective, Judith's surgeon was making a new norm for her re-constructed breast, based on a physical wound that was healing, and his expectations of what medicine constituted as a normal healing process. Judith held fast to his words, which gave her strength, and for which she was grateful.

The medical treatment was in itself a technology of power in that the medical discourse played an important role in the management of the women's individual bodies, and through which the medical needs and remedies of them as subjects were defined (Lupton, 2012) – Foucault's (1976, 1978) 'anatomo-politics'). In most cases it was the intrusive and observable remnants of the medical practices of mastectomy and/or radiotherapy tattooing which caused the women to react in the particular ways that they did. At her interview, eighteen months after the completion of her last clinical treatment, Judith reported that she was physically well, but her excerpt revealed the continuation for most of the women, of being unable to forget that they have had breast cancer because of the physical reminders of treatment. The growing technical sophistication of medicine exposed the women to an array of equipment and therapeutic practices used to justify their use. While their desperate initial reactions might have lessened over time,



there was enough evidence in the women's accounts to suggest that despite the medically-decreed time-line of the five year sign-off, medical recovery from breast cancer for many of them was never finished or completed. Even for those women who celebrated 'successful' treatment (that is, eradication of the cancer) and recovery, there was little let-up. The strategies of bio-power and governmentality of public health campaigns expected them to behave responsibly in continuing to submit to on-going medical surveillance services and practices. The medical services that the women received were not only as conventionally thought of as one-to-one or doctor to patient. They were also about the wider structures of power and control that played on the concept of risk for the women that the cancer might return (Foucault, 1977a; Harding, 1997; Lupton, 1999a, 1999b; Petersen, 1997; Petersen & Lupton, 1996).

The second most dominant discourse by which recovery was constructed by the study participants was the gender discourse, which intersected and complicated the medical discourse, and allowed the emergence of very different speaking positions and subjectivities.

### **The Gender Discourse of Recovery**

While not as dominant as the medical discourse, the experience of recovery from breast cancer was constructed by the women and the health professionals in significantly gendered ways. These discursive constructions were the distinctly female identities, relationships, positions in the world and meanings about females (Connell, 2009; Eckermann, 1997; Ussher, 2007) that emerged during the recovery stage. The gender discourse, like all other discourses, acted as a means of organising power between the speakers – in this case, the gendered power between the women recovering from breast cancer and their health professionals. The gender discourse worked inter-textually to position these parties as variously powerful and powerless, often shifting from one position to another in short periods of time. My argument is that at the intersection of the medical and gender discursive constructions, profound anxieties arose for both the women and the professionals during the recovery stage.

### **The Gender Discursive Objects – The Treated Breast and the Woman Who Was Recovering**

From a Foucauldian perspective, the discursive objects constructed in the recovery stage by the gender discourse were the treated breast and the treated woman recovering from the experiences of discovery, diagnosis and treatment. Inherent in this gendered

construction were the recovering body and the recovering mind of the woman. This was particularly seen for the women in the case of mastectomy, where treatment took away one of the most gendered and culturally dominant symbols of their femininity and motherhood. The gendered identity was the physically-changed woman, and this identity was enduring because there were on-going challenges for her of coming to terms with her altered feminine physical appearance.

*I have changed physically as well as emotionally as a result of the treatments, and there are constant reminders every time I undress, look in the mirror, touch myself, buy clothes, make love. I've got a flat chest and large scar. I do not feel that I look as sexy as I did before, and I don't feel sexy either. I feel less of a woman. And it's obvious that you are not a whole woman afterwards. It's embarrassing. You are aware that people who know what's happened look surreptitiously at your chest.*

Carol

*My body looked and felt different. I thought that having a mastectomy was a bit like having teeth out. Something ripped out leaving a gap; something was missing. Just like when you break a tooth, your tongue goes straight to it; my hand keeps going to the place where my breast once was. The prosthesis helps, but I'm having to put a lot of time into bonding with my new female self.*

Stephanie

Carol was confronted with daily visual, physical and sensual reminders that she was no longer what society constructs as a 'whole woman' (Greer, 1999). She experienced anxiety about her loss of sexual allure, and despite having had treatment, was made to feel self-conscious because the gendered gaze was fixed firmly on her imperfect female body image.

Stephanie was taking a long time to accept that something so femininely precious was missing, taken from her, with the sensual gap filled with an artificial replacement. Wearing a prosthesis is common for many breast cancer patients, and was a practice constructed by the women in this study who chose to have a prosthesis, as necessary in enhancing their continued dignity and sense of femininity. However, the prosthesis was also a normalising strategy – a form of governmentality which moulded the women like Stephanie into a 'normal' rather than an 'abnormal' form of female-ness and conformity to culture's established expectations and rules.

Women internalise gendered attitudes to, and constructions of, the female breast from adolescence (Connell, 2009; Crawley, et al., 2008). Society has always valued bodily perfection over aging and damaged bodies. There are stereotypes, cartoons and jokes about old women as crones, with drooping breasts and shrivelled cleavages. These are in stark contrast to the fulsome, pert breasts of the young (Bordo, 1990). Such gendered stereotypes are ages old, and continue to prevail in our society to such an extent that the end result of their treatment for breast cancer was constructed by a lot of the women as a permanent form of female physical disability. Carol and Stephanie expressed continuing distress about the bodily changes brought about by their respective treatments. They had a lot of difficulty, not just immediately after treatment, but also for subsequent periods of time, in facing up to the scarring caused by the medical practices of surgery, radiotherapy, chemotherapy, and to other physical signs on the treated female body.

### **The Gendered Subject Positions and Subjectivities of the Recovering Woman**

From a medical gaze, treatments are designed with a definitive endpoint, mostly with a curative intent. For some of the women however, this medically-imposed endpoint created a complexity of subject positions, subjectivities and behaviours, mostly related to their continual striving to regain their critical female and social roles.

*I want to believe, so very much, that everything is the same, so I have chosen not to let on about my situation. I'm ashamed of it really, because as a woman it's naturally a handicap. My experiences and appearance would undoubtedly frighten other women. I'm sure that they would be unpleasantly affected by seeing or hearing me, so I do not show myself or talk about it.*

Nancy

*I just wanted things to go back to how they were, but they are never the same after breast cancer. There's so much involved. It seems as if every part of my life is affected.*

Christine

Nancy and Christine both wished everything to be unchanged. Nancy reflected on the distress of feeling that she no longer fitted the gender norm of the ideal female body. At the intersection of the medical and the gender discourse, the gendered notion of the ideal female body constructed Nancy as abnormal, creating for her subjectivities of the “ashamed”, “handicapped”, frightened woman. Her need to conceal the effects of

treatment arose from a fear that the altered appearance of having one breast instead of two would be suggestive to others of serious disease and mutilation. Breast cancer was treated speedily by medicine, but was disfiguring for the women, making their bodies forever abnormal. Nancy's example also showed how certain experiences can be, and are spoken about at certain times and not at others.

Foucault (1978) argued that discourse is constituted by the things we say, but it is also constructed by what we elect not to say. He was alluding to the power of silence in our everyday lives in that it shuts down or keeps hidden certain discourses, and allows others to be heard. While she may not have been aware of it, Nancy's silence presupposed the primacy of her power in her social relations - who she told, and did not tell, about the effects of her recovery from breast cancer. Some of the women did not readily divulge their experiences after the event. For them, fear and silence still prevailed. It was not easy for them to re-visit the experiences because their breast was the continuing focus. To talk about it in such a way was a very personal and intimate disclosure, and maintaining one's silence was emotionally safer.

Christine listed, counting on her fingers, the after-effects for her – fatigue, physical and emotional scars, changes in cognitive functioning, impact on medical insurance, overt bias in employment, on-going medication. She recognised that she was now different and newly-oriented. Her comment, like Nancy's, revealed the extent to which these women's experiences of recovery were inextricably woven into their social worlds. Even after treatment, they struggled with the incongruence between societal and gendered expectations and the reality of their every-day post-breast cancer lives. For example, loss of libido, often the result of adjuvant drugs taken for five years or more after surgery, and associated weight gain had a negative effect on some of the women's self-image and self-esteem. There were on-going expectations on Nancy and Christine, and continued competing messages. Most significantly, their new body image came at a large emotional cost. Even with breast reconstruction, the expectations of cosmetic results were sometimes not fulfilled, with some of the women continuing to view themselves as having only 'one true breast'. This was a post-structural construction by the gender discourse of the 'less than woman' (Kristeva, 1982), or non-woman identity, a place of abjection disturbing conventional identities and cultural concepts of how 'a woman' should be (Greer, 1999).

As described in Chapter Five, there are many accounts in popular media and women's health magazines from women who have had breast cancer. They are consistently constructed as conquering heroines because their stories are of courage in the face of adversity, and of the meanings they construct from their experiences of 'beating' or 'overcoming' cancer which impact on their post-breast cancer lives. In this study, battle metaphors which constructed the women as heroic continued to prevail in the recovery stage. Both the women and the health professionals talked about the women as "survivors", "victorious" in having "won the battle" and "beaten the odds". However, the interplay of the medical and gender discourses also produced the identities of Nancy and Christine as women tarnished by breast cancer. Women like them have been termed by medical sociologists as "those who are well, but who are marked by illness" (Frank, 1995, p. 166). Nancy and Christine as marked women lived in the normal world, but were part of another not so normal world. They were heroines "with a thousand faces" (Campbell, 2008, p. 23) within these two worlds, positioned forever in on-going recovery, permanently tainted and perpetually at risk of recurrence.

*What price do the women pay? I see them fighting hard to regain their health. Cancer patients in general are stoic, but women recovering from breast cancer, and men from testicular cancer, are particularly so, in my opinion, because of the particular nature of the treatments on those particular parts of the body, and the after-effects they can bring.*

Rafi, Breast Surgeon

From his clinical experiences as a surgeon, Rafi recognised the on-going impact on some of his patients, and while he differentiated between the diseases of breast and testicular cancers in both a sexed and gendered way (because breasts and testes are obvious signs of sex), he saw women as continuing to suffer, and acknowledged their enduring struggles. Conversely, female patients were not always viewed so positively, and were sometimes considered by their health professionals to be neurotic and emotional in the ways that they faced the reverberations of breast cancer. The physical remnants of breast cancer did not go away, and the women did not get over the experience easily. The dual source of authority of the predominantly male-dominated oncological profession over women patients, and females in general, meant that some of the professionals incorporated gendered beliefs about female behaviour into their medical view.

*Although doctors today normally speak with their patients about hope that they will be treated and cured, breast cancer is unusual in that it can recur decades later. Some women develop a real pessimism about their future, and an irrational conviction that the cancer will definitely come back.*

Ross, Oncologist

*I have a lot of anxious patients, who come in for other medical reasons after breast cancer, but who go on and on about it. They really have to throw off the idea that they have had breast cancer otherwise it can become all-consuming. These women really should just shut up and be grateful that we have fixed them.*

Alasdair, Oncologist

While Ross conceded that breast cancer continued as an on-going threat to women, even though they had been treated, he viewed such women as unnaturally negative and irrational – traits of the neurotic, somewhat phobic female.

Alasdair had obviously encountered female patients whom he constructed as ungrateful recipients of medical expertise, and whose on-going reactions he considered unreasonable and illogical. His views were that women should be grateful to be alive, and that the medical means justified the ends. He recognised such patients as anxious, but like Ross's patients, overly obsessed. He sought gratitude and acknowledgement of his and medicine's skill and ability to repair and bring resolution to a 'female problem' (Merchant, 1990; Turner, 1987).

Ross and Alasdair were both oncologists who brought to their specialist work a gendered gaze upon the reactions of women recovering from breast cancer - deemed typical of the hysterical female (Foucault, 1978; Smith-Rosenberg, 1972, 1985). From a Foucauldian perspective, they constructed these women as problematic and inferior by their drawing on a gendered view of the ideal woman or patient as a basis for comparison. Both practitioners demonstrated intolerance and exasperation when their female patients did not behave rationally. This showed a noted tendency for some of the doctors to treat their female patients' problems as 'typical' feminine neuroses and complaints (Stewart & Roter, 1989). The male doctor dominated, exercising a strong paternalism over subordinate their female patients (Goodyear-Smith & Buetow, 2001). Ross and Alasdair's view reflected the gendered role model widely portrayed and perpetuated in the media, in articles, and by other women, as a right and womanly way

to respond to breast cancer (Kasper & Ferguson, 2000, p. 317). Those women who did not were seen to be enacting inappropriate responses.

### **Gender Discursive Practices and Power**

In direct contrast to the women who did not disclose or talk about their experiences, there were others who, in adjusting to their new lives as women recovering from breast cancer, found camaraderie in women's support groups and their activities (Lugton, 2002). Identifying with others who had had the same experiences allowed for a special recognition through female practices and membership of especially female groups. This was seen by the wearing of 'Can-Survive' badges, 'Breast Friend' badges and the iconic pink ribbon, and by participating in Breast Cancer social events. The Foucauldian notion of power/knowledge (Foucault, 1980) can be seen here through a gender lens. Power was operating within a social group of women (only). As Foucault said, power and knowledge are inseparable as each strengthens the other. The women who belonged to a support group were empowered through the sharing of their own and others' knowledge and experiences.

*Everybody's operations were different, treatments too, and the healing. It is an individual cancer and an individual experience, but we are all alike in the way that we have all been there. We seem to have a knack of finding each other, identifying who we are, and the talking is interesting and supportive. It seems to be such a special group with an intimate interest.*

Carol

Carol epitomised the spirit of familiarity and trust existing between women who did not really know each other, but who had faced similar issues, and shared their experiences and advice. It was a significant sorority, paradoxical in that these women who had had breast cancer lived with the invisible, albeit chronic, aftermath of a disease which many were reluctant to talk about with their intimate and significant others – a type of female taboo (Kasper & Ferguson, 2000). The women's membership of a support group could be seen as a gendered technology of power through the citizenship of being part of a group with a single focus. Membership identification facilitated the women to be active and capable, acting in their own interests and in solidarity with others. The camaraderie experienced by Carol, in taking up opportunities to talk openly and honestly within a close and distinct group of other women, gave her a sense of empowerment and control.

The engagement of the women in support groups could also be considered as a counter-move by some, to their perceived lack of power both as patients and as females in a male-dominated oncological world. All of the women in this study continued to be particularly obligated to follow the advice of their health professionals in order to keep the disease at bay (Conrad, 1992). The experience of some of the (male) health professionals however, was that some women were not pro-active in continuing to practise self-surveillance, and this gave rise to gendered constructions of them as wayward and intractable.

*I would describe the behaviour of some women as wilful. After all of the mammography publicity, why can't these bloody women just carry on getting themselves checked out? It would save us, and them, a lot of grief.*

Alasdair. Oncologist

Alasdair's position at the intersection of the gender construction of women's behaviour as deviant (Conrad, 1992; Riessman, 1983; Schur, 1984), and the medical construction of the ideal patient who conformed, caused him considerable disquiet. Alasdair's comment implied an expectation by some medical practitioners that women should conform to a trajectory of recovery, and that the behaviour of women who did not continue to have follow-up breast checks after breast cancer was a form of female delinquency. He did not voice any recognition of women's agency or having the right to make their own decisions in this regard (McNay, 2000). Alasdair was also oblivious to the possibility that past encounters or conflicts might inhibit future interactions between himself and his patients. Most of the conflict talked about earlier by the women in the diagnosis and treatment stages, was experienced in the quality of their interactions with their health professionals – words used, body language and empathy shown.

The dominance of the doctor's word as the voice of authority about all things medical fitted with the medical discourse, but there was also a gendered patriarchal element to Alasdair's comment in his expectations about how women should behave - that women should conform to the norm of being compliant females. If their relationship with their doctor was to be regarded as metonymic of their relationship with medicine as a whole (Segal, 2005; Gwyn, 2002), then it was probably not surprising that some of the women were reluctant to continue to engage with medical care such as checks, examinations, mammography, and so on. The medical and gendered voice of authority thus played a major part in obligating the women in this study to appease their medical practitioners



by acting responsibly and submitting to regular and on-going medical surveillance practices.

Deconstruction of the women's and the professionals' accounts of the recovery stage of the breast cancer experience revealed a significant tension between their respective meanings of the term 'recovery'. In the following section of this chapter, I examine the impact of these differing notions on the identities and discursive practices of both parties.

### **Subjectivities of the 'Recovered' or 'Recovering' Subject**

Common meanings of the word 'recovery' include reclaiming the possession of something lost, particularly control or composure after an experience, and of regaining one's previous status. This can include one's physical, mental or emotional and social status. There is also a sense of restoration through the getting back at, retaliation and securing some sort of compensation from the cause of the original event from which one has been hurt or damaged (Amering & Schmolke, 2009). For decades, psychological theorists and physicians have conjectured about why some women who have faced the stress of breast cancer seem to adjust and recover relatively well, whereas others continue to demonstrate considerable emotional and interpersonal distress afterwards (Galgut, 2010; Holland & Weiss, 2010).

Conflicting themes ran through the constructions of the aftermath of breast cancer by both the women participants and the health professionals. For the health professionals, recovery was constructed as the successful removal of cancerous material from the breast(s) of their patients. For the women, the notion of recovery was confusing. On the one hand they had been assured by the professionals that they now longer had breast cancer – that the cancerous tumour had been successfully surgically removed from their bodies, and that ongoing localised, systemic and pharmaceutical treatments were insurances against recurrence. All of the women expressed gratitude for their re-gained healthy status, but they also all talked about the emotional issues they experienced for long periods afterwards, especially of their fears of recurrence, and of the medical system. The concept of recovery from the disease of breast cancer was problematic for these women because there was no reassurance that they would ever recover emotionally or psychologically, despite the best altruistic medical intentions of treatment outcomes. For example, was a woman who survived the medically-imposed five-year 'cure' mile-stone, but had enduring physical and emotional scars, 'recovered'?

The psychologising and problematising of what happens to women after treatment is a discourse which the disciplines of psychology (Rose, 1985, 1996a), and more latterly psycho-oncology (Holland, 1998, 2010), have created. The recovery stage of the breast cancer experience has been termed the 'new-orientation phase' by psycho-oncologists. From a Foucauldian viewpoint, the subjectivities of wellness and distress are discursive constructs or descriptions generated together with medicine by psychology, in attempts to define and explain these states of being (Foucault, 1973; Rose, 1996a). As this study shows, there were significant emotional reactions for all of the women at all four stages of the breast cancer experience - most notably fear and anxiety. However, it was in the recovery stage that there was more permanent impact on the minds of the women. With time, they were able to look back on the experience in its entirety. Deconstruction of their accounts revealed the multifaceted and ambivalent nature of their longer-term emotional adjustment and recovery.

#### **The Discursive Object of Recovery – The Woman Recovered**

Medical treatments for breast cancer resulted in significant changes to the women's lives. For all of them, having had breast cancer had emotional consequences which were either empowering and liberating or enduringly the opposite.

*I attended my grand-daughter's school prize-giving wearing a wig. The chemo treatment was finished but my hair hadn't grown back. She was thrilled I was there, and so was I.*

Rose

Like all of the women in this study, Rose experienced shock and fear when first diagnosed, however, her comment revealed what may be interpreted as a positive mental adjustment over time. The cancer which had disrupted her life for a period of time did not preclude her experiencing future happiness and pleasure. Even so, positive emotional adjustment was not simply the absence of distress for the women. While most of them found optimistic meanings in their illness experience, they were not immune to significant emotional challenges in the on-going adaptive tasks they faced. These predominantly included regulating the distress of physical loss or altered-ness, maintaining personal worth, restoring relations with important others, and, as Rose demonstrated, bolstering personal and social acceptability once physical recovery was attained.

Some of the health professionals in this study expected some emotional response from their patients to their recovery, and to the aftermath of breast cancer, but not it appeared, enduring anxiety. From a medical perspective, they expected the women to recover emotionally just as their physical wounds would. Once physical interventions were completed however, the women's contact with the medical system decreased dramatically. With its focus on the return of a patient's post-breast cancer health status, often considered to be the resumption of routine activities, the discipline of oncology credited itself with a job well done (Bradby, 2012; Cantor, 2008). The path to emotional recovery was far from smooth for many of the women, however. The recovery stage was not as representative of the initial immediate reactions experienced in discovery and diagnosis, and to a lesser degree in treatment, because it was much longer drawn-out. Nevertheless, there were anxious thoughts related to recovery for many of the women.

*I am alert to... my antennae are up to all things breast cancer. Quite frankly, I'm sick of thinking about breast cancer. I wish that it would just leave me alone. Nothing prepares you for the loss of peace of mind afterwards.*

Mary

*Mentally I am afraid. I just seem to have this continual worry. I am afraid that the cancer will come back because just as I thought I was getting the five year sign-off, the mammography picked up something in the other breast. The specialist said statistics were against it being breast cancer again, and the subsequent tests showed that it wasn't cancer. But now I worry every annual mammography that they will find something. You can never completely rest easy.*

Bev

The experience of having been diagnosed and treated for breast cancer caused Mary to be continually apprehensive. She was watchful, vigilant and continued to practise self-surveillance. Her senses were so attuned to the topic of breast cancer, that she was over-focused and overwhelmed by the emotions associated with its very mention.

Bev also positioned herself as a woman with on-going emotional difficulties. Her comment revealed a vacillating subject position, contingent at any given time of being at risk of recurrence of illness. The inaccuracy or unpredictability of the medical truth of being totally cured of breast cancer challenged the popular concept of the metaphoric 'journey', with a final destination or ending for all of the women. Bev, for example,

continued to be fearful of the medical system because it was this system that had first confirmed the bad news of her cancer, and she was afraid that it could do so again (Salander, 2002)

For Mary and Bev's doctors, there was a definitive medical beginning and end to their cancers, but for the women themselves there was no conclusive end to the emotions associated with their medical experiences, thus exemplifying the highs and lows of "the breast cancer rollercoaster" (E. Adams, 2007). Mary and Bev gave voice to a major underlying question of whether or not it was possible for the women to put the whole experience behind them and return to the healthy mainstream position as if nothing had happened. Cure and recovery are constructed by medicine as the ideal, but the associated emotions did not allow that version of recovery for most of these women. Despite the fact that they were still alive ('recovered'), there were permanent visible and tangible signs of what had gone before – deformed, reconstructed or no breasts at all, indelible radiotherapy tattoos, hard scar tissue which might never diminish, and the risk of lymphoedema. For Mary and Bev there was no mental rest from breast cancer. As they stated, they would be fearful of every medical encounter after treatment, always hyper-vigilant, subjecting themselves to on-going surveillance, and always dreading more bad news.

### **The Resilient Woman**

The experience of those who have gone through all stages of a crisis and worked through and integrated the original trauma in a positive way is commonly described as resiliency (Stanton et al., 2007; Peterson et al., 2006). Despite their immediate emotional reactions and long-term after-effects, some of the women in this study viewed their experiences as being 'character-building', and making them 'stronger'.

*I never had to cope with anything quite like it before. I am proud of myself. I am a 'Cansurvivor'. I like that term. I am a stronger person than before. It's certainly had its ups and downs, which continue even now. Recovery from breast cancer has its lonely places. It will get better as time goes by, because I accept myself now in different ways. Less shy; more brave. I'm out there now, fund-raising for breast cancer.*

Nancy

*I'm still afraid of getting cancer again and dying, but I wouldn't be so afraid of having the surgery again, or the radiotherapy. And I'm not afraid of talking*

*about breast cancer, or showing other women my war wounds. In a way it has been a positive thing. It has made me see life differently; appreciate life; made me stronger and braver. I would feel differently if this happened again.*

Anne

Nancy and Anne were able to mourn adequately for their losses, and their determination to re-engage positively with life prevailed. As Clare, the psycho-oncologist said of women in such a position, “Their psychological energy is employed beneficially”. Clare drew on the ideal which the discipline of psycho-oncology believes women should follow. Further deconstruction of the women’s accounts of recovery in the longer term revealed the emergence of two main subjectivities and identities, and two subsequent and successive discursive practices. The first was what Frank (2000) called ‘systems of honour’. These were the women whose identity once ‘spoiled’ and stigmatised by a disease or illness like breast cancer, later openly claimed that identity, and invested in it as a different, albeit for some, privileged state of being (Goffman, 1959). These were women like Carol, who talked to other women about their experiences, and like Nancy, who wore Pink Ribbons, participated in breast cancer public consciousness-raising activities and other forms of involvement and activism.

In stark contrast to the professionals like Ross and Alasdair, cited earlier in this chapter, who spoke in gendered and, it might be said, condescending ways, of women’s natural pessimism and fixation, the resiliency of women like Nancy and Anne was recognised and acknowledged by other health professionals.

*I really admire women who have come through the breast cancer experience. I am a woman, and a surgeon, but I often wonder at the end of the day whether I would be as stoical as most of my patients are. I’d like to think so. But I also think there’s a lot of pressure on them to be..., to act or be seen in certain ways. I can quite see how it could be a lonely place.*

Raewyn, Breast Surgeon

Raewyn’s comment was a discursive construction of the ideal patient – one whose on-going reactions were not considered problematic. But Raewyn was also aware that unbalanced attention to positive adjustment and recovery could have untoward consequences for her patients. The expectation of the unfailingly strong and heroic patient permitted the woman recovering from breast cancer little latitude for showing her true feelings. Presenting a brave face has become prescriptive in common thinking

about cancer recovery, to such an extent that women can “fall prey to the tyranny of the positive thinking” (Holland & Lewis, 2000, p. 14) expected of individuals recovering from cancer. For some of the women in this study, like Nancy, who had pointed out in an earlier excerpt, this could be a “lonely place”.

Interestingly, there was a similarity in the subjectivity of some of the health professionals, in their places of mental isolation or remoteness, both from their colleagues and by necessity from their patients.

*Yes, I'm supported in my everyday work by anaesthetists and nurses, but sometimes I do feel a bit lonely. It is a fairly never-ending process for us [surgeons] ... I enjoy the work, but yes, sometimes it's lonely work because I gown-up, operate, gown-up, operate and leave at the end of the day without talking to my patients or to any of my colleagues for any real length of time.*

Rafi, Breast Surgeon

Nancy alluded to the lonely moments she experienced in the time after her treatment ended, but Rafi also revealed that he faced on-going professional and emotional challenges. These were related to his perceived isolation from peers with whom he could share experiences. The outward appearance of the resiliency expected of Rafi, as an antidote to traumatic circumstances, masked the real emotional impact of his situation.

### **The Techniques of Emotional Power in Recovery**

Foucault's (1980) had a belief that subjugated knowledges, that is, those he described as “naive knowledges, located low down on the hierarchy, beneath the required levels of cognition and scientificity” (p. 82), are important sources of information. This was well presented in his argument that local and reality-based knowledge (for example, knowledge about the experience of being ill and recovering from that illness) lies within the patient rather more than within clinical theory (Foucault, 1973). It was Foucault's contention that it is the patient's perspective which has the potential to hold great importance and great power. Most of the women, when in the immediate recovery phase, assumed subjectivities of wanting to present an image to the outside world that they were the same as they ever had been. They wanted to believe that others saw them as the same physically, and behaving in the same ways as before. Their hopes and contradictory emotions demonstrated the strategies of Foucault's notion of bio-power

(Foucault, 1984, 1988), and the coercive discursive practices of normalisation (Foucault, 1977, 1980).

*Most people were pleased to see me back, and I guess I looked the same to them, but in my mind I wasn't. I wanted to be the same, but I wasn't. I felt mixed up – angry that it had happened in the first place, and sort of proud that I had come through it as well as I think I have. Frightened and brave at the same time. Does that make sense?*

Anne

Coercive technologies of thinking and behaviour could be seen in Anne's comment. She was expressing her desire to be unchanged by her illness experience. Breast cancer's high visibility in the media, community and socially was a technique of bio-power which caused Anne to think differently from before. Sub-discourses of physicality and an associated wish for one's healthy body and mind back implied uninterrupted and constant coercion and expectations from external sources, which continued to be exercised on Anne over time. The paradox was that while Anne wished for a return to her normal pre-breast cancer life, there were also common assertions of beneficial personal transformations as a result of her breast cancer experiences. She claimed that having had breast cancer changed her mental outlook for the better – a demonstration of the familiar adage "what doesn't kill you makes you stronger".

There was a further significant paradox in the impact of techniques of bio-power for the women. In the first instance, medicine's grim constructions of breast cancer as a major killer gave rise to significant persistent feelings of fear of recurrence and uncertainty about the future for all of them. Medical statistics show that once a woman has had breast cancer her chances of developing it again are increased fivefold (Anderson, 2002; Liggins Institute, 2013; Miller et al., 2000), and every year more than 650 women die from breast cancer in New Zealand; almost two every day (New Zealand Ministry of Health, 2013). All of the women in this study, while not obviously totally conversant with the numbers, were very aware of the risk of recurrence of breast cancer. As alluded to by some of them, they knew of this medical 'truth' from public health campaigns advising on-going mammography and screenings, and from the experiences of other women. Conversely, the positive medical statistics of survival after medical intervention strengthened most of the women's mental resolve through their investment in two further medical messages. Even after being 'successfully' treated, breast cancer could return in another form and in other sites in the breasts, and that again, the early

diagnosis and treatment for breast cancer was less likely to result in death. However, there was an emotional burden in being the responsible woman who continued to practise self-surveillance and who returned for on-going medical examinations.

It is interesting to reflect back into the traditional history of cancer that recorded the ancient Greeks using the evocative word *onkos* to mean a ‘mass’ or ‘burden’ in describing cancerous tumours, and from which the discipline of oncology would take its modern name (Mukherjee, 2010). In Greek theatre the same word *onkos* was used to denote a tragic mask, often burdened with an unwieldy weight on its head, denoting the psychic load carried by its wearer.

## **Summary**

In this chapter, I have identified the medical discourse and the gender discourse as the predominant discourses deployed by women and health professionals in their constructions of recovery from breast cancer. Not unexpectedly, the medical discourse significantly over-rode the gender discourse by dealing only with the physical or biological body, and not with female subjectivities.

In the recovery stage, the medical discourse generally constructed the discursive object as the treated body, a substantial medical construct. But the body, treated medically for cancer, was constructed by an important sub-discourse of having the potential for recurrence of the disease within it. As a result of the potentiality of further medical danger, the subject position of the health professional as the ‘knower’, the specialist, remained firmly in place. The medical gaze encouraged the women in on-going bodily self-surveillance, and they continued as patients. Despite the five year post-treatment sign-off, a medically imposed time line, all of the women in this study were compliant in undergoing on-going breast examinations and scans. Medical techniques of power were thus applied to the watched body, a surveillance which was to be unfinished for these post-breast cancer women.

The second dominant discourse to arise in the construction of the recovery stage was the gender discourse. This discourse was less prominent than the medical, but analyses of the discursive constructions which categorised the women by their sex, femininity and sex roles provided valuable insights into their experiences of recovery. The gender discourse’s discursive object was the woman who had completed treatment for breast cancer – the treated woman. She was positioned as newly-orientated and changed by the



detection, diagnosis, treatment, and on-going after-effects. These effects were constructed as gendered remnants, affecting the appearance and function of the female breast and body by permanent physical scarring, and thus impaired sexual and maternal roles as partners and mothers. There remained underlying fears and anxieties, but as the women adjusted to their new lives, some became activated, finding support in the camaraderie of others, either individually or in groups.

Analysis of the gender discourse also revealed that the health professionals could be either empathetic or dismissive of women's experiences in recovery from breast cancer. Most of them expressed concern that their patients would continue to do well after treatment, but their responses varied from admiration for their patients' resiliency, to exasperation at their on-going emotional difficulties. Some constructed their patients as neurotic and emotional females. The techniques of medical and gendered power combined to construct the identity used by some of the professionals to describe those 'female patients' who over-stated their struggles in overcoming the whole cancer experience.

Emotional aspects of breast cancer thus continued well into the recovery stage for both the women and the health professionals. At the intersection of body and mind, the women's thoughts and actions continued to be dominated by cancer. They did not stop seeing themselves as breast cancer patients when treatment was completed, or when they and their professionals celebrated the medically-defined five-year anniversary after diagnosis. The excerpts cited in this chapter showed that most of them were fearful and had on-going anxieties related to their post-breast cancer status. Some struggled to accept their changed body image and hid the emotional effects, while others, likewise worried, had resilient thoughts and displayed spirited behaviours. However, the accounts of the health professionals also showed that some of them had continual emotional issues related to their work in breast cancer. Most noteworthy were their feelings of professional isolation and their on-going unease about the curability of each of their patients. For the participants in this study, breast cancer endured. The notion of 'recovery' was both a medical and a gendered discursive construct which in combination gave rise to subjectivities of the anxious, albeit resilient female and the apprehensive health professional.

In the next and final chapter, I draw together the key findings of my analyses of the accounts of the women and the health professionals in each of the four stages of the

breast cancer experience. I pursue my main argument that the interplay of the medical and gender discourses created significant, albeit different, subjectivities of anxiety in the women and in the professionals. I discuss the implications of this finding for the education of women and for the practice of health professionals who engage with women with breast cancer.

## **CHAPTER TEN: DISCUSSION – THE INTERPLAY OF THE MEDICAL AND GENDER DISCOURSES PRODUCED ANXIOUS SUBJECTS.**

### **THE THESIS AND BEYOND**

#### **Introduction**

The aim of this chapter is to review the aims, and discuss the findings of my study, and the implications of those findings for education and practice. The first objective of the study was to investigate how breast cancer was constructed by the discourses most predominantly deployed by women and by health professionals. A second objective was to identify the subject positions taken up by the participants, and the subjectivities these positions created. My choice of a Foucauldian-inspired post-structural discourse analysis was a deliberate research approach because it opened up a novel way of approaching a study of breast cancer. It provided me with a methodology by which to deconstruct and analyse the accounts of women who had had breast cancer, and health professionals who cared for such women.

Drawing on Foucault's concepts of problematisation, discourse, subjectivity, and power/knowledge, I explored these at each of the four stages of the breast cancer experience I identified, and chose to call the discovery of symptoms, diagnosis, treatment and recovery. The primary context of my study was what I have termed 'the medical encounter', that is, the encounters between the women and their health professionals, and health professionals with women with breast cancer, including the women's encounters with oncological technology. I considered how each of these stages offered speaking and subject positions for the women and for the professionals. I discussed the subjectivities and techniques of power that emerged and changed for each party by their deployment of the dominant discourses at a particular time within each stage.

First, I discuss how my research reflects, differs from, and extends current knowledge in the discursive field of breast cancer. From a post-structuralist Foucauldian lens, I consolidate my identification of the dominant discourses at each of the stages. Second, I consider the implications of the argument within the findings, and reflect on them as a contribution to new understandings of breast cancer and the limitations of the study.

Finally, I describe how this new awareness might be applied to education and practice, and in offering some thoughts about what my research has *not* uncovered, suggest some directions for future investigation.

## **The Consolidation of Findings**

### **The Problematisation of Breast Cancer**

My exploration into how breast cancer has been variously constructed by discourses, showed firstly that the object and experience of breast cancer has historically been, and continues to be, ‘problematised’ in our culture by the ways that it is spoken of and written about (Foucault 1989). In the introductory chapter to this thesis, I shared some of my personal experiences of being diagnosed and treated for breast cancer, and my ensuing interactions with a number of health professionals. To understand better my experiences, and those of others, I believed that the application of Foucault’s (1998) concept of problematisation as a theoretical concept was directly pertinent to my study. From my point of view, Foucauldian problematisation had two main relevant objectives. First, the analytic approach it offered opened up a novel way of approaching breast cancer. Rather than looking for one correct response to breast cancer as an issue or problem, it allowed the examination of how it has been, and is, “questioned, analysed, classified and regulated” at “specific times and under specific circumstances” (Deacon, 2000, p. 127). Second, it had the ability to challenge and theorise taken-for-granted ‘truths’ about breast cancer through the process of exploring “how and why certain things (behaviour, phenomena, processes) become a problem” (Foucault, 1985b, p. 115).

Generally our society views breast cancer as problematic (Olson, 2002; Mukherjee, 2010). The Foucauldian response is that to make meaning of such a problem, it is important to first understand how, why and by whom breast cancer is constructed as a problem, and the responses to that problem. While a lump in the breast is viewed as a basic biological fact across cultures (Baum, 1986; Cantor, 1993; Martensen, 1994), the ways in which it comes to be constructed as a problem is mediated entirely by the contexts in which it is placed. In addition, different individuals and groups can develop markedly different responses to it. The implicit truths informing the breast cancer discourses are the reasons breast cancer has long been problematised. Furthermore, the interests of many groups have shaped the problematisation of breast cancer during specific periods. Problematisation is a dynamic and context-dependent process, and

power struggles are framed according to the discourse dominant at the time (McCarthy, 2005). In the following sections I outline the discourses which I identified as the most dominant by which the participants in this study constructed breast cancer, and the subjectivities which emerged at each stage of the breast cancer experience.

### **The Dominant Discourses by which the Women and the Health Professionals Constructed Breast Cancer**

Analysis of the accounts of the women and the health professionals revealed that there were two very dominant discourses by which they constructed their breast cancer experiences, and which were so influential that all other discourses were submerged or marginalised by them. The discourses were:

- The **medical discourse** – a discourse which was solely medically-derived (e.g. symptoms, pathologies, diagnosis, site, stages, treatments, and prognosis). The medical discourse provides a space for the public health discourse – a discourse which was government-derived (e.g. policies, campaigns, neo-liberal health promotions, knowledge, and expectations for healthy behaviour). The public health discourse was found to be an important discourse in the participants' accounts, and one situated within, and over-lapping the larger discourse of medicine and medical practices.
- The **gender discourse** – a discourse which was derived beyond the sexual perspective of female and male to the roles and subject positions of each gender. The feminist discourse was similar to the gender discourse in its construction of gender as socially, rather than biologically, constructed. It offered related gendered subjectivities, but also provided a different lens by which the gender inequalities of women's and men's social roles and lived experiences could be interpreted. While very prominent in the socio-cultural literature of breast cancer, the feminist discourse was not so strongly deployed by the women and health professionals as the medical and gender discourses, but nevertheless provided critical insights into their meaning-making of breast cancer.

I turn first to what was the first step on the trajectory of breast cancer, identifying both the dominant and subordinate discourses, which I argue overlap and constrain the dominant discourse

### **Discovery of Symptoms – A Medicalised and Gendered Construction**

The women's texts revealed deployment of both the medical and gender discourses when they first discovered symptoms themselves, or symptoms were discovered by others. The discovery of the breast lump was the point at which all of the women became both subjects and objects of the medical/public health and gender discourses. The high medical and public health profile of breast cancer as a significant disease of women (Anderson, 2002; Kasper & Ferguson, 2000; McPherson et al., 2000) meant that all of the women in this study knew that their symptoms could signify breast cancer. They were all knowledgeable about, and alert to, breast cancer. The medical discourse constructed a lump (or other symptoms) in the breast as a potential threat to life, impelling all of them, within different time-spans to seek a medical diagnosis and treatment. At the juncture of medicine and gender, a woman's deployment of the gender discourse constructed the lump as a threat to her female breast and body, and as generally putting her gendered roles of sexual partner and/or mother at risk (McPherson et al., 2000; Ussher, 2007; Watkins, 2000). Feelings of having so much at risk, gave rise to emotional reactions in the women.

### **The Emerging Thesis – The Discovery of Symptoms Produced Anxiety in the Women and the Health Professionals**

From a post-structural discourse analytic perspective, discourses produce effects, and emotional responses to a discursive object such as a lump in the breast, are I suggest, such an effect (Parker, 1992, 1997, 1998). The discovery of unconfirmed symptoms, whether on their own, with or by another person or by the technology of mammography, scans and/or thermography, aroused considerable feelings of anxiety in all of the women. In this study I used the term anxiety to encompass the wide range of subjective feelings of general emotional discomfort or unease related to a perceived or real threat to significant fearfulness (American Psychiatric Association, 2013). While not yet discursively constructed, categorised or labelled as medical 'patients', the women's fears about facing the medical diagnostic and treatment processes brought into play a contrast of reactions and discursive practices. Faced with the possibility of a diagnosis, they *initially* responded in one of two ways. They either concealed their symptoms and emotional reactions for a period of time by not immediately seeking a diagnosis, or they were galvanised into action to do so. In bringing themselves into the medical gaze by seeking a medical confirmation, the women's symptoms became a reality and became known by others.

One outcome was that for all of them, this decision-making was experienced as a singularly lonely and differentiating process (Segerstrom, 2003), reflecting Foucault's (1977a) concept of the examination as a dividing practice that individualises people. Both reactions were products of the disciplinary power of the medical discourse, of neo-liberalism (Harvey, 2005), and of the public health discourse which strenuously advises all women to exercise responsibility for one's health by practising self-surveillance, undergoing public health screenings and other types of medical surveillance (Armstrong, 1995; Harding, 1997; Petersen & Lupton, 2000). The discovery of something 'abnormal' in the breast produced distress and anxiety for the women, because breast cancer has historically been, and continues to be so constructed by the medical discourse that even indefinite symptoms are interpreted as a threat or sign of danger to one's wellbeing and life (de Nooijer, 2003; Lupton, 1993; Scott et al., 1991).

The gender discourse, by which the women made meaning of the discovery of symptoms, was a strongly conflictive discourse to the medical, because the discursive object was the subjective female body rather than the objective biological body (Holmes & Marra, 2010; King, 2004; Ussher, 2007). The practices engaged in by the women were specifically related to their protection of family about a possible diagnosis of breast cancer, and associated threats to their gendered roles. But responding by concealment and avoidance had other consequences for some of the women because it precluded further exploration of the perceived threat, and, not being explored, the source of the threat remained ill-defined (Bloor & McIntosh, 1990). As a result of feeling anxious about the symptoms, some of the women's behaviour became vacillating and confused – presenting as outwardly passive while emotionally in turmoil within.

When their patients presented with symptoms, the major subject position taken up by the health professionals was that of possibly having to be knower and imparter of any confirmation of breast cancer. Being in this position caused most of them to feel some unease. Not only did they have to face their patients' anxiety and reactive responses to uncertainty, but they subjectively held their own fears for their patients about the diagnostic process.

### **Diagnosis – A Medicalised and Gendered Construction**

The Foucauldian history-of-the-present review presented in Chapter Four, showed that several factors emerged and coalesced in a relatively short time frame which enhanced

the awareness of cancer in contemporary Western contexts. This expansion created opportunities for the emergence and growth of new positions, professions and practices. Most notably, the medical discourse produced the subject positions of doctor and patient (Lupton, 1997).

The dominant discourse concerning diagnosis was the medical discourse, deployed strongly by the health professionals, and following suit, by the women. The process of seeking a confirmed diagnosis was a technique of medical surveillance as was the method of diagnosing, categorising and labelling the woman as a 'breast cancer patient' (Sawicki, 1991). The doctors were the knowing professionals, whose role it was to diagnose and treat. The woman's role was as submissive and docile patient (Foucault, 1977a; McLaren, 2012), to be diagnosed by the professionals, and treated.

Both parties were equally committed to seeking the medical 'truth' of the breast symptoms. For them both, diagnosis was very much based in the pathology of the woman's breast. The medical discourse constructed cancer as a collection of cells injurious to the body, and breast cancer as a disorder of breast cell growth. This discourse also constructed the science of diagnosis and treatment of breast cancer as omnipresent and omniscient as a result of its multi-dimensional scientific lens – microscopic, differentiating, technological, digital, statistical, individualising, normalising and prognostic. The outcome of the technologies and practices of mammography, ultrasound and thermal imaging of the medical and public health discourses, was that the women were compelled to consider the possibility that the disease of breast cancer could kill them or at least disfigure them. At the point of seeking a diagnosis they were identified by the medical discipline of oncology as being at risk of such a possibility.

All of the women were given 'the bad news' (Fallowfield & Jenkins, 2004; Salander, 2002; Sweeny & Shepperd, 2009) by a health professional that they indeed, had breast cancer. The discursive construction of breast cancer as 'bad news', was commonly practised by the professionals. The health professionals communicated an urgency to diagnose and treat, whereas as patients, the women, knowing what the diagnostic outcome might be, were positioned in the dilemma of wanting, but at the same time not wanting, to know the meaning of their symptoms (Bish et al, 2005; de Nooijer et al 2003; Hunter et al., 2003; Meechan et al., 2003). This links well to Foucault's (1991)



notion of governmentality, in that the women were compliant and acting as responsible citizens.

### **The Emerging Thesis – The Receiving and Imparting of the Confirmed Diagnosis of Breast Cancer Produced Anxiety in the Women and the Health Professionals**

The time between discovering breast symptoms, and having the cancer diagnosis confirmed, was talked about by the women as being the most stressful part of their breast cancer experience. This was because the reality of cancer now signified the real possibility of death and the probability of physical disfigurement. The paradoxical ambivalence of the women feeling afraid, but presenting themselves as brave subjects, continued in their approaches to facing the truth, and therefore to the rigours of treatment with its immediate and long-lasting effects. During the diagnosis stage, the women reported being very much absorbed in their fearful thoughts about breast cancer. Their accounts showed that they recalled having cancer foremost on their minds whatever they were doing, particularly projecting ahead to the possibility of dying and the impact of the death of a mother and partner on her family. Overall, the process of diagnosis produced the fearful subject. Like the discovery of symptoms, the receiving of a confirmed diagnosis was, I argue, a discrete and solitary medical and gendered experience.

The discursive practice of imparting a confirmed diagnosis was also unsettling for some of the professionals. Breaking the bad news exposed them to women's emotional reactions. This caused them to also speak about feeling disturbed or anxious. As a result of the position as the knower and truth teller, some spoke of employing self-protective strategies when communicating the diagnosis, such as giving the news abruptly, using euphemisms or avoiding direct questions. Their accounts showed how they believed that such strategies assisted them to deal emotionally with difficult interpersonal situations. This finding is supported in Fallowfield and Jenkins' (2004) study of communication styles in cancer care. From a post-structural perspective, the deployment of such measures by their health professionals created a position of relative powerlessness for some of the women. In general terms, the ways in which the bad news was imparted had an impact on how the women reacted emotionally, and how they adjusted to their new identity of 'breast cancer patient'.

### **Treatment – A Medical and Gendered Construction**

In this study, the discipline of oncology, and the dominance and exclusory impact of the medical discourse, meant that remedies and treatment modalities for cancer were defined and deemed appropriate by the medical profession with such strength, that other regimes, termed 'alternate' were submerged for all of the women. In so doing, medicine, with all of its knowledge and specialist practices, exercised considerable power over the women (Foucault, 1980b, 1980c; Goodyear-Smith & Buetow, 2001). Deconstruction of both the women's and the professionals' accounts showed that for both parties, clinical breast cancer treatment was an extremely technical undertaking. Each type of treatment involved highly specialised professionals, with circumscribed responsibilities for their share of the patient's care. There was another complex array of expertise now involved in the lives of the women - general practitioners and practice nurses, breast surgeons, oncologists, radiotherapists, chemotherapists, and breast care nurses. The language used during the treatment stage was very clinic based and bounded, occurring in patched areas. The medical discourse had generated the notion of the treatment phase and had created the spaces for different treatment modalities and practitioners – each with their own specialised language and protocols of practice.

Most of the women spoke of remaining passive, deferring to their doctors on treatment-related matters. Further analysis revealed that some of the women thought that their wish to be more included in the decision-making process was not well recognised by their physicians. To an extent, they believed that awareness of this need depended on the personal characteristics of the professional. Power and control were critical elements in the interaction, with the balance of power on the side of the professionals whose role it is to treat a population of women willingly submitting themselves to such regimes. The medical discourse can thus be seen to produce this imbalance of power – the obedient patient, and the all-knowing powerful doctor. In producing such subject positions in particular the docile, conforming patient, Foucault's notions of bio-power (1984) and governmentality (1991) as techniques of power are strongly implicated here, with their intended purposes of increasing the longevity and well-being of compliant populations.

Paradoxically, it was in the treatment stage that some of the women talked about feeling empowered by their interactions with other women. They recounted not feeling so individualised or alone, because there were occasions not possible during the diagnosis process when they were able to interact with other *women* in similar circumstances. For

example, while they were waiting their turn for radiotherapy treatment, “... all in our white gowns, sitting along the wall”, some of them talked together about the treatment and the disease in general, and compared their experiences with those of others. They constructed this as an important form of re-orientation and acceptance of their altered identity as a medically-treated woman.

### **The Emerging Thesis – Treatment for Breast Cancer Produced Anxiety in the Women and the Health Professionals**

All of the women spontaneously associated breast cancer directly with illness, disfigurement and debilitation, and then went on to make similar constructions and connections to the types of treatment they received. Some had quite frightening ideas about the treatment while they were undergoing it. The effects on the women of surgical, radiotherapy, and/or chemotherapy were severe, and involved not only physical scarring but also emotional distress. Mostly this anxiety was related to the invasive and disfiguring impact on their bodies from the treatment they were to receive, and the associated impact on their gendered and social worlds through possible loss of self-esteem, femininity, accustomed roles, and health (Bartky, 1988, 1990; Holmes & Marra, 2010). The perception of the control and mastery of the professionals over the treatment stage made many of the women consider that their interactions with their treatment providers were impersonalised and inadequate, which also left them feeling vulnerable and disempowered, exacerbating their anxiety.

Both the women and the professionals invested heavily in an inherent hope that the medical treatments would be effective in eradicating the cancer. While medical technologies such as surgery, radiotherapy and chemotherapy were viewed by all of the women as invasive and debilitating, in the long run some found their experiences of treatment enabled better self-knowledge. These women became strong proponents of medical technologies, and some expressed gratitude to the professionals who administered them.

It was during the treatment stage that personal characteristics of stamina and fortitude were most to the fore in the women’s constructions of themselves. While all of the women, and some of the professionals, experienced a subjective fear about the impact of treatment, most spoke about remaining outwardly calm and strong. For the professional, this was about keeping up the appearance of the qualified and proficient

expert (Swick, 2000), while the women behaved in ways which they believed were expected of them when facing the reality of cancer treatment (Burrows, 2010).

### **Recovery – A Medical and Gendered Construction**

I chose to define and delineate the last stage of the study participants' experiences as the 'recovery' stage. Deconstruction of the accounts of the long-term, rather than the immediate emotional impact of breast cancer, both on the women and on the professionals, raised the issue of whether a woman was constructed as 'recovered' or 'recovering', depending on the lens through which she was observed. My findings showed that the medical discourse predominantly shaped the women's and the professionals' perceptions of recovery as the period after the completion of the women's last treatment. The medical gaze was solely on the healing of the physical or biological body and continued surveillance for recurrence of disease, and did not allow room for other aspects that may have needed to recover. The mind/body dualism of the medical gaze (Foucault, 1973) was to the fore in its dehumanising separation of the woman's body from her person or identity. It was body-focussed, and limited the consideration of other factors in the women's recovery.

There was however, also a strong gendered influence during this time, shown in the women's retrospective accounts of the lingering effects of the breast cancer experience on their lives as females. Rather than recollections of their immediate responses to the discovery of their symptoms, diagnosis and treatment, all of which had happened to them within a short space of time, the women were more reflective over a longer period of time during this stage. At the time of the post-treatment interview, they talked about after-effects, and how they were making meaning of it all. In the first instance, analysis of their accounts revealed that the whole experience of breast cancer was a prolonged medical and gendered one, with the possibility of no real ending for some of them. While still focussed on the body, there was more talk about on-going emotional effects.

### **The Emerging Thesis – Recovery from Breast Cancer Remained an Anxious Time**

The period after the completion of the last clinic-based treatments, placed the women in the position of having to make considerable adjustments to their altered bodies and lives. These included: coming to terms with anxieties provoked regularly by the tangible remnants of surgical scars, a missing breast or no breasts, radiotherapy tattoos, altered body shape and hair texture, breast clinic advertisements and reminder letters. They talked not only about the longer-term emotional impact of treatment on their female

bodies, but also about the consequences breast cancer was continuing to have on their ability to perform their ascribed gendered roles, with associated negative effects on their self-image and confidence (Eckermann, 1997; Kimmel, 2000).

Other adjustments were continuously bordered by interactions with medical specialists, such as on-going medical consultations, breast examinations and mammography. Whatever the medical specialty, breast cancer endured for the women, most especially with the fear of recurrence. The necessity for them of having to engage again and again over subsequent years in order to obtain diagnostic proof to allay those fears meant that breast cancer was commonly constructed by both parties as a chronic emotional condition as well as an acute disease (Miller et al., 2000). The constant emotional adjustments required of the women caused most to feel persistently uneasy, and led some to almost constant self-monitoring. Even after treatment had ended, on-going and regular self-surveillance was a discursive practice and strategy of bio-power deemed by medicine and public health to be 'responsible' behaviour, expected of all women (Osborne, 1997). All of the women in this study were thus placed in a position of feeling that they needed to be constantly vigilant to evidence of the abnormal or the re-occurrence of symptoms. Being normal was a state they could not take for granted. As a consequence they were always wary, and always under surveillance.

Paradoxically, enduring anxiety in their patients was interpreted by some of the health professionals as gendered, female, self-obsessive, neurotic behaviour. Under-tones of the patriarchal construction of 'the hysterical woman' served to emphasise the distance between the unemotional male professional and the emotional female patient. Conversely, some of the health professionals who constructed their patients in this way, engaged in discursive practices of self-protection when in medical encounters with anxious women. In general though, most of the health professionals in this study were empathetic to their patients in recovery, expressing hope that they would continue to do well, and admiration for their courage and resiliency in 'getting through it'. From their perspective, the medical treatment regime had been completed, the cancerous matter had been eradicated from her body, and the woman was considered 'recovered', that is alive. From a Foucauldian perspective, given the threat of death that breast cancer posed for both the women and the professionals, the governmentality or social services of medicine were the forces by which a disciplined and compliant population of women was created, and thus, kept alive. The emotional aspect of recovery, while not a discourse in itself, was an important extra-discursive factor in terms of understanding

the 'interior' world of the subjectivity and inter-subjectivity of the women in this study, and to a lesser extent of the professionals (Wilkinson & Kitzinger, 1995).

In summary, the identification and deconstruction of the two dominant discourses of medicine and gender deployed by the women and health professionals when speaking about breast cancer revealed that other discourses which might have been anticipated, such as the feminist discourse or alternative health discourses and practices, were marginalised or did not emerge at all. The process of analysis facilitated the emergence of my argument that the two dominant, albeit competing discourses, came together to produce significant disquiet or anxiety in both parties. The possibility of death and/or disfigurement was synonymous with cancer for both doctor and patient. As a result, not only the women's physical, but also their emotional health was compromised throughout the whole process of the discovery of symptoms, diagnosis and treatment, and continued into recovery, despite the elimination of the cancerous tumour. The anxiety which ensued was produced by the combined and over-lapping focus on medicine and health and the gendered roles of women. The dominance and impact of these two discourses has, I believe, important implications for education, practice and research.

### **Implications of the Discursive Themes of the Argument**

My use of a post-structuralist discourse analysis, drawing on key concepts from Foucault, allowed the identification of the discursive themes running through the findings I described in the preceding sections of this chapter. Post-structural discourse analysis reveals multiple truths about the object under scrutiny. In this study, the truths of breast cancer were constructed by the discourses of medicine and gender. The women and the health professionals were positioned at the intersection of these discourses, with dynamic forces at play. While the medical discourse dominated, the gender discourse was tightly woven within the participants' accounts, most particularly with the women.

This study, being discourse-centred, did not serve the participants by privileging any of their accounts as objective and true. The interviews could only be considered as 'snapshots in time', and while I use the term conclusions to my findings, there were no real research conclusions possible (Guba & Lincoln, 1981). As Grbich (2004) says, the deconstructing of texts created by the researcher and the researched opens them to a range of interpretations, all of which are transitional and infinite. Text always inevitably refers implicitly or explicitly to further texts outside of itself, or as Foucault saw it, a

text's "frontiers ... are never clear cut ... it is always caught up in a system of references" to other texts (Foucault, 1972, p. 23). The inferences I have made are therefore tentative, and cannot be seen as providing in any way a final word on the experience of breast cancer by women or by health professionals in general. The identified discursive components had however, some important implications for the women's lives, and for the practices of the professionals.

### **Implications of Findings for the Women – The Threatened Woman**

All discourses have the ability to empower and subjugate, liberate or to make docile (Foucault, 1977a). In this case, the medical discourse largely limited or over-rode discursive options for the women. Other than the gender discourse, there was a distinct absence of deployment by them of alternative discourses by which breast cancer was constructed. In the first instance, breast cancer was shown in the analyses to be a multifaceted object, experienced in different ways by the study participants. While there were some commonalities of meaning, for each woman the cancer had its own individual cause, sensation and effects, with singular emotional and social outcomes. Each experience of the discovery of symptoms, the receiving of a confirmed diagnosis, the undergoing of treatment, and their combined and continuing after-math gave rise, I suggest, to emotional reactions for the women not normally recognised or acknowledged by their practitioners. As a consequence of the professional borders created by medical expertise, the specialists seemed to largely pass over the emotional impact of breast cancer on women.

While the findings of this study showed, mostly, that the health professionals were efficient in providing detailed and explanatory information about breast cancer, they also showed that there was a possible need for them to follow up on how this information had been assimilated by their patients, beyond being labelled a breast cancer patient. It was not uncommon that when given information about their breast cancer status, some of the women misinterpreted it or did not understand its medical significance. Foucault's (1980) notion of power/knowledge was very applicable. The almost hegemonic dominance of the medical discourse in defining the phenomena known as breast cancer, determined what happened to the women once diagnosed. The discourse was so dominant that it closed down any consideration of the possibility that external environmental factors might have influenced the materialising of the cancer, effectively locating it in the individual woman (Sawicki, 1991, 1998). Foucault argued that knowledge can both create and effect power which in turn creates knowledge. If the

women had been given more knowledge about their bodies, it is likely that the power relations between them and their medical practitioners would have been different. It seemed to me that some of the women could have benefitted from more education in breast anatomy, symptoms, diagnostic and treatment procedures, and the long-term effects of all of these factors. The women's lack of knowledge, expertise or power to greatly influence decisions about themselves, and the tendency for some of the professionals to circumvent their patients' and their own emotional challenges, led me to conclude that there was a need for the two parties to listen more carefully to each other. This would have created a more equal balance of power developing closer relationships and working towards achieving clearer understandings of each other's perspectives of the same situations.

The implications for women's lives described above were compounded by another finding in the study worthy of note. As shown in Chapter Five, there is a wealth of feminist literature related to breast cancer (for example, Kasper & Ferguson, 2000; Klawiter, 2008; Wilkinson, 2000; Wilkinson & Kitzinger, 2000; Ussher 2006, 2007). From a post-structural and Foucauldian perspective, studies show that the feminist discourse confronts the holding of knowledge of women's bodies by a monopoly of a male-dominated elitist and patriarchal medical profession, and challenges the subject positions and subjectivities of the irrational, submissive female patient. By exposing how the medical discourse constructs women in this way, the feminist discourse provides the opportunity for women to take on more powerful and resistant positions. However, it is of interest that there was a distinct absence of deployment of the feminist discourse by the women interviewed for this study. This was shown in the analyses to be likely the result of the women's focus on being diagnosed and treated for cancer, and becoming well again, rather than on any issues they had with the medical balance and practices of power between doctor and patient. Such issues of power, and the behaviour expected of each party were more apparent in the accounts of the health professionals when they were imparting a diagnosis or talking about treatment.

### **Implications of Findings for the Health Professionals – The Vulnerable Professional**

The stages of the breast cancer experience also created shifting subject positions for the health professionals. This occurred to a much greater degree for the health professionals than for the women, because of their various professional and specialist roles and identities, especially in the treatment modalities of surgery, chemotherapy, immunotherapy, radiotherapy and gene therapy. Breast cancer was read and understood



by the professionals as clinical knowledge from their particular points of view (Foucault, 1980). However, there were some parallels in their respective subjectivities with those assumed by the women. In the first instance, the interplay of the medical and gender discourses produced anxiety or apprehension in the professionals which I consider is not commonly acknowledged from within medical circles themselves. This is a critical finding of the study, and one which has important implications for the lives of professionals who work in the area of breast cancer.

Perhaps the position where the professionals were most vulnerable to women's reactions was when imparting a confirmed diagnosis. They had no choice but to break the bad news at the time of consultation. Pressures of work and short appointment times meant that there was no luxury of time for multiple consultations, or 'waiting until the time was right'. The feeling expressed by some of the health professionals, that their medical training only went part way to equipping them for the 'troubled' patient and family interface they encountered repeatedly, was an important finding. Some of the professionals also did not seem to recognise that their patients were most defenceless emotionally during the periods of diagnosis and treatment. Women with breast cancer spend a lot of time in medical encounters, and, as recounted in this study, such encounters are anxiety-provoking circumstances. The most common of the women's responses to breast cancer treatments were fear and whole-hearted hope for their effectiveness. Conversely, these responses caused immediate anxiety for some of the professionals at the doctor-patient interface. Characteristics of a patient's illness remained vividly present for some of the professionals, colouring his/her expectations when similarities occurred in subsequent cases. The professionals could never know their patients in their entirety, however, and the ways in which they interpreted their patients in the 'one-off' medical consultation had the potential, as shown in some of the women's accounts, to lead to the omission of full explanations, or to contribute to their behaviour being considered inappropriate or humiliating to the woman.

In the passing over of the emotional impact of breast cancer on women, the health professionals also suppressed the impact of their work on themselves. Anxiety for some of the health professionals, while very different from that experienced by the women, was also significant. Their strong positioning in the medical discourse raised issues related to their defence of the status of doctor and the voice of authority (possibly through fear of patient resistance), and their protection of the discipline of oncology and allied technology. As a result, the ways in which gender was rendered problematic by

some of the professionals, they engaged in discursive practices of what I defined as self-protection from women's emotional and fearful responses. They also interacted with their patients in ways that protected them from the emotional impact of their every-day work of breaking the bad news, performing disfiguring surgery, administering debilitating treatments, and holding the expression of frustration at patients' unwillingness to submit to on-going medical surveillance. Health professionals cannot escape being part of medical and social traditions, and strong socio-cultural patterns related to the professional identification of the doctors in this study seemed to persistently obstruct their learning about their patients and orientation to them (Novack, et al., 1997). This study has shown, like others (Bartky, 1990; McLaren, 2012; McNay, 2000), that the medical gaze is not an objective or neutral scientific or clinical view, and that the deployment of a gender discourse by health practitioners can result in limited and biased interpretations of the female patient (Birke, 2000; Butler, 1990; McLaren, 2012).

### **Implications of the Balance of Power – The Silencing of Anxiety**

Despite the different stages and shifting subject positions, the subjectivities of the threatened fearful woman and the vulnerable apprehensive professional, remained constant throughout this study. Foucault's (1991) concept of governmentality in medicine's emphasis on life created anxiety about death for both parties. This is because life and death are constructed in particular ways. In our culture, life is thought about as being ideally long, and premature death as being 'not fair'. Medicine attempts to prolong life through treatments which eliminate illness and disease and facilitate the regaining of health. The body is 'normalised' (Foucault, 1977) through the eradication of cancer. While this might be true pathologically, the body was not normalised for the women in the absence of cancer, but disfigured by treatment. For them in their various gendered roles, their bodies were rendered and remained abnormal. Disfigurement and the associated threat to femininity drew out fear in the women. However, the dominance of the medical technologies of power, in terms of expectations of behaviour for doctors and for patients, silenced the open expression of those anxieties (Hollway & Jefferson; Strega, 2005). The impact of the balance of power between the women and their health professionals shut down open talk between the two.

Foucauldian discourse analysis has the ability to uncover the effects of knowledge and power (Foucault, 1980c). The finding that the practice of medicine did things *with* the bodies of the women, rather than *for* them as women ran throughout my analysis.

Identified as breast cancer patients, the women did not enjoy equal partnerships with their health professionals. As patients they had communication needs to be satisfied in order for them to achieve their desired degree of understanding about their symptoms, diagnosis, the disease of breast cancer and its treatments, and how they might recover. As described earlier in this chapter, miscommunications and misunderstandings about these issues sometimes occurred between the women and professionals.

### **The Findings of the Study as a Contribution to Education and Practice**

The main challenges for education and practice that I believe this study has revealed, and which have already been substantiated in previous research, are four-fold. Firstly, in congruence with feminist educators' arguments, my study has shown to some degree that in the context of women's health, women's experiences and knowledge can be largely ignored by professionals (Bartky, 1990; Crawley et al., 2008; Malterud, 2000; Ussher, 2007). Secondly, power relations within medical encounters relating to breast cancer can be strongly based on gender (Sherwin, 1992; Ussher, 2007, 2009). Thirdly, the voices of women and professionals must be heard by each party if change is to come about (Sherwin, 1992, 1994). This would allow other discourses, subjectivities and discursive practices to be brought into play. Finally, there is an unmet need for the emotional support of women with breast cancer, and of health professionals who care for such women (Holland & Weiss, 2010; Whippen et al., 2004).

The reluctance of some of the women to take immediate action is a significant finding. As described earlier in many places in this thesis, Eckermann (1997), used the term defiance, but this does not convey the reality of the women interviewed. These women were defiant during the stages of diagnosis and treatment in their facing up to and determination to overcome the adversity of breast cancer, but reluctant to start those specific medical processes. Both reluctance to submit to medical surveillance and intervention, and defiance in the face of them, are clear examples of Foucault's concept of liberating, positive and productive power/knowledge in play. All of the women, in my opinion, whether a docile body or an active self (Eckermann, 1997), were the stronger for it.

It is interesting that the voices of the four nurse participants were largely silent. It is also interesting to note that any nurse should have a role designated against a body part (breast care nurse). Perhaps we should contemplate why any nurse should willingly accept such a title given nursing's passionate adherence to holistic approaches to practice. The

relevance of this comment for the thesis is to the hegemony of biomedicine – that is, one power within medicine over another - and the ability to shape health service discourse. Within the consistencies, contradictions and paradoxes as revealed in this discourse analysis I could see some possible seeds for change.

### **Women's Medical Experiences Should Not Be Ignored**

One of the objectives of rigorous research (Lather, 1986) is the potential disruption of power relations. Disruptive practices can be enacted through deliberate use of different discourses that value and acknowledge the experiences of the patient and challenge the power related to gender and professional authority (Malterud, 1993, 2000). As described earlier, Foucault (1980) talked of power as being linked to discourses, and always in play. By the taking up or deployment of different discourses, such as medical or gender, certain power plays can be disrupted. A vivid example of medical power play and authority was seen in this study in Jessie's surgeon, who said to her "*We talk about you behind your back, we decide what we're going to do, and then we tell you*". Such comments revealed the extent of the subjectification and disempowerment of the women as patients by their doctors' discursive practices. It was an important finding in this study that the women were so compliant, and showed little resistance to being interpellated by the medical discourse. For Foucault, there is always the power to resist, because power is not fixed. While he did not ignore the role of individual agency, he was also interested in how individuals are programmed by the social institutions in which they find themselves, and why they accept being programmed in such a way. My focus on localised resistance, its form and consequences showed that the women submitted rather than resisted – an example of Foucault's argument that normalisation occurs when docile bodies are shaped by disciplinary power (Foucault, 1977). Perhaps there is a space for the employment of discursive strategies that would draw women in, and promote inclusiveness in decision-making, learning and related areas.

### **Non-gendered Power Relations**

The medical and gender discourses were interconnected in this study with matters of power, however, in general terms there is potential for such matters of power to be incorporated into strategies for change (Foucault, 1978; Malterud, 1993; McLaren, 2012). By recognising power relations and cultural stereotypes related to gender (for example, the hysterical female), the professional would be better able to acknowledge the understandings held by women about their own bodies. Code's (1995) concepts of a

rhetorical space and a gendered location being the medical encounter were well applied in the study, and evident in the participants' accounts of their experiences of the balance of power between the two parties. But just as the feminist literature and the pertinent excerpts cited in my study show, medical and public health discourses' tendency to group women with breast cancer together, ignoring their lives, hopes and fears, women likewise, cannot lump health professionals together as patriarchal and lacking in understanding. So, while this study has shown the dominance of the medical discourse in the medical encounter, there is the potential for other discourses to be brought into play, and both parties need to be open to this possibility. Foucauldian discourse analysis looks for the broader discourses that emerge, and while there is uniqueness in every medical encounter, it is the nature of the social interaction and the discursive interchanges that matter most. With attention to the wider discourses at play it is possible to approach gender-sensitive issues in ways other than medical.

### **The Meeting of Minds and Voices of Women and Health Professionals**

Correlation or congruence of timing between the discourses deployed by the women and the professionals might have been enhanced, had the professionals been more attentive to the way the women's stories were constructed. Malterud (2000) wrote of an augmented understanding between health practitioners and their patients, by practitioners reflecting on their own roles as participants in the process of telling and listening. My thinking was that a widened scope of interpretation by the professionals of what women say, might have been achieved had they better acknowledged the limited scope of their readings of their women patients.

With its initial high incidence and later recurrence rates, breast cancer is coming to be viewed as a part of daily life, rather than as an abnormal event (Anderson, 2002; Kasper & Ferguson, 2000; Liggins Institute, 2013). There would be very few, if any, women and health professionals who have not had contact with breast cancer in some way. The conclusions I reached, presented above, opened up to me possible gaps in current medical education and practice. I began to think that health professionals exposed to, or educated more in critical thinking and analysis, would have the knowledge and awareness of power relations to pay more attention to their interactions with patients. They would be more aware of types of talk (discourses), the existence of multiple discourses, and what talk and practices in medical consultations with women with breast cancer might disclose and conceal. Such critical thinking would be a means by which they could perhaps gain better contextual insight into the cognitive and affective

consequences of each party's constructions of breast cancer, and the determining of possible sites of contest and resistance.

Rather than investing wholly in the medical practices of diagnosis, treatment and recovery, there would be recognition that feelings and emotions are an important part of daily lives and experiences, and that the expression of them could provide good learning about the speaker. Paying more careful attention to what is being said, and not said, could also assist in anchoring a professional's conversation with a patient to the actual encounter, thus providing opportunities to make stronger connections with his/her own and patient's reality. Such an approach has the potential to open up spaces for other ways that people think about and construct breast cancer, that is, other discourses which have equal truth and value. By broadening health professionals' repertoires of discursive practices, they would be better able to acknowledge and respect the emotions generated by the term breast cancer. Educating health professionals to be more judicious when interacting with women with breast cancer, could be considered as another type of medical 'resiliency training' - needless-to-say one more patient-centred than tumour-centred.

### **The Need for Emotional Support**

With a further turn to practice, another finding of the study was that emotional support or psychological services were difficult for both parties to access. I consider that the lack of ready and as-of-right emotional support for both of the parties in my study had some serious consequences with regard to the omission of the duty-of-care of the women, and to the peer supervision of professionals. Care of the women was fragmented because of the number of different medical specialists involved. Service provision typically reflected the needs and agendas of the health professionals, and analyses of its efficacy were mostly confined to those same professionals. Also, the women, always being in a state of 'recovery' or 'recovering', talked about the need for access to on-going professional emotional or psychological support as part of a 'breast care package'. While psychological support has been shown to do much to alleviate subjective apprehension (Galgut, 2010), there was no formalised emotional support offered as a matter of course to the women in this study. Some of them certainly participated in Support Groups, and their breast clinics within the private sector provided some initial support from breast care nurses. In general though, immediate and long-term help had to be sought and entered into voluntarily by the women.

The effect of breast cancer on the health professionals also raised some questions for me about the need for formalised support for them as well. Most of the professionals in this study were emotionally moved by the plight of their patients, but it was significant that strong emotional responses were generally not discussed by attending professionals with colleagues. Diffuse and chronic anxiety in the professionals was less visible, and it seemed that they also needed a way in which the emotional effects on them could be shared with colleagues, and supported by professionals trained in the management of the immediate and on-going stress which was so much part of their breast cancer work. Concealment and silence led some to what might be identified within the psy-complex and psychological discourse (Rose, 1985) as maladaptive coping patterns and practices and to further various emotional distress (Bloor & McIntosh, 1990; Meechan et al., 2003; Smith et al., 2005). In essence, formalised and regular support for the professionals I interviewed seemed almost non-existent.

During the course of this research project, I learned more and more of the basic need in the women to be able to express and share difficult experiences with their attending professionals. Post-structural discourse analysis has been shown to be a powerful mechanism for exposing patterns of discursive resistance between speakers, but it also reveals opportunities for acknowledgement and remediation through education and change. Now I understand in a different way from when I was planning the study, the importance of not underestimating patients' and professionals' capacity to benefit from more in-depth conversations with each other, and with others who are having similar experiences. However, this thesis should be conceived of only as a collection of discursive snap-shots on the days of the interviews, revealing some 'truths' about breast cancer amongst many others. While the findings were enlightening in many ways, there were limitations to the study which have to be considered.

### **Limitations of the Study**

There are several limitations in this research. Firstly, use of a post-structural discourse analytic approach brought to light two dominant discourses in relation to breast cancer for the women and for the health professionals involved in this study, but there could well be others. People's accounts and how they are made sense of through discourse analysis are affected by the availability of discourses. Discourse is an interactive process, deeply implicated in the maintenance of power relations through its ability to privilege particular versions of the world and to silence those less dominant (Foucault, 1981; Mills, 1997). The exploration of *women's* accounts of their experiences of a

specific disease condition inevitably restricted my research gaze to medicine and gender. As a result, the full range of other possible discourses was not represented.

Another limitation could be seen in the fact that only two participant groups were interviewed for the study. As a result, the field was not so widely encompassing. The focus of my research questions meant that the findings of this study were biased to the two groups only. Their perceptions of breast cancer were only one view (Holquist, 1990), modulated by the research setting chosen by me. Also, it is the nature of qualitative research that the number of participants is relatively small. Interviews with more women and more health professionals might have revealed more diversity amongst these two groups. The ‘elephant in the room’ was that I recruited only women who had survived treatment for breast cancer, or in other words, only those who had received treatment, and up to the time of interview, in medical terms at least, successfully! I did not interview women who knew that they were terminally ill and who could have died during the course of the study. Facing inevitable death would have most definitely given another perspective of experience. Partners, family members, friends and associates of the participants were also not interviewed, nor people from a wide range of cultures or socioeconomic groups. This undoubtedly would have extended the range of discourses to reveal other meanings of the disease and experiences of it.

As a precautionary note, when identifying the subjectivities of emotional subjects, it was important for me to always keep in mind the sense that the women and the professionals in my study related their emotional experiences at a time and space the interview created for them. Being interviewed gave them the freedom to express emotions in a retrospective way (Keats, 2000). A further limitation to the study could be seen then, in the retrospective nature of the women’s recall after a period of at least one year, and up to five years after their last clinical treatment. It is argued, (especially in the breast cancer scenario), that women retain exceptionally clear recall of the details surrounding events such as the unexpected diagnosis of a life-threatening or critical illness (Galgut, 2010). However, the length of time between the discovery of symptoms and subsequent adjustments could not be discounted as important influences on the women’s recall (Morse et al., 2002). The findings might be considered more trustworthy had I interviewed the participants more than once in order to determine the constancy of their responses (Morse et al., 2002). There have been occasions over the time of this study nevertheless, when some of the women and health professionals have asked about



the study, and anecdotally re-stated what they had said previously. Nothing has changed – now eight years later.

Additionally, there were limitations to the study pertaining to my own biases. In qualitative research there are often ambiguities in the role of researcher (Grbich, 1999; Lincoln & Guba, 1985), and in this case there were biases in that the whole study process was set down by me as the sole researcher - that is, the type of research, the its mobilising, organising, data collection and analysis, and control over the knowledge produced. I held the power in the decision-making about the why and how, the research setting or 'catchment area', the types of information to be obtained, and the control over the use of the outcomes of the whole process. My research method of interviewing was in itself a shared social experience (Fontana, 2002; Seidman, 2006), because discursive practices such as interviewing are always experienced rather than merely perceived, and experienced from a particular position (Foucault, 1972; Wetherell, 1998). My multi-perspectives as a female, psychologist, teacher and breast cancer 'survivor', brought my own pre-conceptions and prejudices to power and subjectivity, and in my role as critical analyst. I hope that I made it sufficiently explicit in my introduction to the study the positions from which I approached this research, and in Chapter Three, the steps I took to overcome the potential for any underlying partiality. Despite these ambiguities and limitations, I believe that the post-structural discourse analysis theoretical underpinnings and Foucault's research methods were appropriate for the project by creating other knowledge and learning, and offering alternative ways of thinking and acting.

This study has been about making audible some experiences of breast cancer and the practices of empowering and disempowering which operate within this discursive field. The consent gained for my deliberate seeking out of such private and sensitive information from the participants, and their trust in my research ethics, were both a privilege and a responsibility. Throughout, the research process entailed a reflexive exercise for me in ensuring respect and protection of the contents of their accounts while knowing that I had the intention of sharing them with a wider audience. Morales (1998), suggested that certain groups are unlikely to hear the results of research through traditional academic channels and that a 'delivery system' must be devised in order to ensure that these people receive direct benefit. She proposed the use of creative, alternative methods of communication for this purpose. Health professionals busy in the field, and women who have or have had breast cancer, are unlikely to read a dissertation such as this one, so articles, classes, talks and interviews will be the channels by which I

plan to disseminate my findings. In the sharing of these findings however, it will become apparent to the readers and listeners that there is some unfinished qualitative business necessitating further investigation.

### **Possible Directions for Future Investigation**

Breast cancer has a long documented history of at least 2,500 years, and the language, discourses and discursive practices by which breast cancer is currently constructed have changed over the length of this history, and will continue to change in the future. In the early decades of the 21<sup>st</sup> century in Aotearoa New Zealand, as in all Western countries, and in other countries beyond, breast cancer continues to hold a special mystique and is still imbued with medical, gendered and emotional meanings which extend far beyond the rational, medical and biological facts of the disease. Because of these various constructions, it continues to be difficult to make sense of breast cancer. Whatever the discursive construction, breast cancer remains a ubiquitous disease because it is an age-old disorder in a modern world.

As described in Chapter One, while there is indeed abundant literature on the many themes of breast cancer in various forms of research, education and advocacy, there is a developing body of published research applying *discourse analysis* to breast cancer and my study is but a small contribution to the on-going process of that analysis. As an incisive tool for my research, discourse analysis provided dramatic and moving insights into the various dimensions of the participants' lives that could otherwise have been overlooked or irretrievable in the traditional reading of text. My turn to discourse within the dimensions of medicine and gender showed that there was the possibility of many other discursive spaces to be explored. Because of our individual (mine included) deployment and participation in particular discourses we maintain the status quo. However, with a wider focus on texts, whether spoken or written, there are opportunities to identify and analyse what further discourses and their practices might offer when exploring other ways in which individuals might view their worlds with breast cancer in it. These might include the other less explored personal and institutionalised relationships breast cancer brings, other ideologies that surround it, and its other politics. There are many possibilities, such as exploring the experiences of women who decided not to undergo treatment, or who sought alternative treatments; the accounts of younger or older women; men with breast cancer; and constructions of the disease in other cultures. Future research could also include Maori women and women from other cultures, which may bring forth different constructions of breast cancer, and experiences

of it. Such exciting and challenging opportunities convince me that post-structural discourse analysis as methodology and method has far-reaching potential for future studies of the discursive object of breast cancer.

### **Judy's Final Word**

The discovery of breast cancer symptoms, diagnosis, treatment and recovery from the disease were shown in this study to be long and difficult paths for both the women and health professionals, always overshadowed by the uncertainty of the threat of recurrence and failure to cure. It is my hope that the findings from this post-structural journey might lead to a deeper understanding of the strengths and difficulties inherent in current breast cancer practice, and provide some indicators of how such factors might be enhanced or addressed within the medical encounter. I share this optimism with the courageous and passionate women and professionals who participated in this study. They came to my interviews because they valued the chance to talk about how they felt (and because there was someone committed to listening). While perhaps not understanding the terminology of discourse and discourse analysis, they also knew that in the sharing of their experiences they were contributing to an increased understanding of the impact of breast cancer on the everyday lives of women and their health professionals.

At the end of the day, my original thoughts were, and I believe my thesis has shown, that breast cancer, when constructed by the medical and gender discourses, remains a killer and/or disfiguring disease of women, and one which over the millennia has continued to be respected and feared. Despite recent medical research which suggests that if diagnosed early enough the chances of surviving five years after treatment are very high, the words 'breast cancer' continue to strike fear into the hearts and minds of Western women and considerable alarm in health professionals. Cancer as a medical and social phenomenon has always been distressing, and a common and enduring discursive practice, even today, is that a diagnosis of cancer is synonymous with death. Its historical and public portrayals prove that it is still feared, in spite of, or possibly because of, it being talked about more than ever, especially in public health discourses and the media. Breast cancer's fearful reputation for striking women of all ages without warning or taking little account of social, economic and to some degree racial boundaries, underpinned the fact that the finding of symptoms, being diagnosed and treated for breast cancer, and the process of recovery, remained some of the most traumatic and challenging events that had ever happened in the lives of the women in

this study. The emotional impact on the health professionals working in the field of breast cancer on a daily or frequent basis was also not insignificant. They were charged with the responsibility of breaking the bad news, contending with their patients' responses to treatment options, providing support through recovery, and expressing reassurances for positive outcomes.

My study showed that the interplay of the medical and gendered discursive constructions of breast cancer produced emotional responses in both the women and the professionals. It also showed that these responses arose separately, bordered by medicine and gender, and were not the result of any joint experience between the two. With regard to future attempts to address some of breast cancer's many vagrancies, I believe that my analysis and findings have opened a space for women and health professionals to recognise their collective, albeit different, lenses, knowledge and power to face them *together*, through a commonality of discursive construction. To that end, it is pertinent I leave the expression of the study's final message to Breast Care Nurse, Judy. "Speaking for women who are diagnosed, of whom I was one, and for the medical profession, to which I also belong, I believe deeply that we *both* have to fight the *fear* of breast cancer. It is the fear we must firstly take into account. We need to stand up to our fears and stand strong".

*Ahakoā he uaua, kia kaha, kia toa, kia manawanui.*

(Although there are difficulties, be strong, be brave, be steadfast)

(Turoa, 2006).

## POSTSCRIPT

Very early on, when conceptualising the study, I was drawn to the advice of Patricia Maguire (1993) that:

Although the dissertation shouldn't become a lifetime project, it cannot be disconnected from your values and philosophy ... When possible get involved in a "problem" that you feel passionate about. For even if the ... research you engage in is not ideal, you will have the satisfaction of working on life issues close to your heart, not merely dissertation issues. Your life passions will enrich the process, not detract from it (p.176).

At that stage, all I knew was that I had a deep personal interest in and commitment to exploring issues from my own experiences of breast cancer, and those of women around me and other unknown women and health professionals. While the research paradigm and methodology of post-structuralism, and Michel Foucault's concepts and methods of discourse analysis were not so familiar to me, I was pleased to eventually settle on them as the approaches by which to conduct my research in ways other than quantitative, and if qualitative, not solely descriptive. In so doing, I set out on an enormous journey of academic and personal development. Undertaking the study has been intellectually and emotionally challenging and I am grateful for its revelations. The learning that I have obtained in the writing of this thesis has changed my personal, professional and academic life in the ways that, through my post-study lens, Maguire (1993) alluded to, (although not in the order I have quoted her here),

The point is to learn and grow from doing, and to celebrate the doing, no matter how flawed, small scale or less than ideal...

... For we never know when we begin where the work will take us and those involved. Perhaps that is what allows us to begin...

Maguire, 1993, p. 176

I hope that my study, however it is accessed, changes the thinking of professionals who care for and about women with breast cancer, and subsequently the lives of those women.

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# Appendices

## Appendix A: Health and Disability Commission Ethics Approval



Northern Y Regional Ethics Committee  
Ministry of Health  
3<sup>rd</sup> Floor, BNZ Building  
354 Victoria Street  
PO Box 1031  
Hamilton  
Phone (07) 858 7021  
Fax (07) 858 7070

8 May 2008

Ms Linley Stevenson

Dear Linley

**New Zealand Health Professionals' and Patients' Constructions of the Experience of Breast Cancer: A Discourse Analysis.**

**Investigators:** Linley Stevenson. Supervisor: Debbie Payne, Dr Kerry Gibson.

**Ethics ref:** NTY/08/01/007

**Locations:** Mercy Breast Clinic in Epsom, Auckland.

The above study has been given ethical approval by the Northern Y Regional Ethics Committee.

### Approved Documents

- Interview topics.
- Participant Information sheet dated 24/4/08 for women who are current clients.
- Participant Information sheet dated 24/4/08 for health professionals currently providing services.
- Consent Form.
- Transcribers Confidentiality agreement dated 29 March 2007.

### Accreditation

The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

### Progress Reports

The study is approved until **30 June 2011**. The Committee will review the approved application annually and notify the Principal Investigator if it withdraws approval. It is the Principal Investigator's responsibility to forward a progress report covering all sites prior to ethical review of the project in **8 May 2009**. The report form is available at <http://www.ethicscommittees.health.govt.nz>. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

### Amendments

It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Amrita'.

Amrita Kuruvilla  
Northern Y Ethics Committee Administrator

Email: [amrita\\_kuruvilla@moh.govt.nz](mailto:amrita_kuruvilla@moh.govt.nz)

## Appendix B: AUTECH Approval

# MEMORANDUM

### Auckland University of Technology Ethics Committee (AUTECH)

To: Deborah Payne  
From: **Madeline Banda** Executive Secretary, AUTECH  
Date: 16 December 2008  
Subject: Ethics Application Number 08/284 **New Zealand health professionals and patients constructions of breast cancer: a discourse analysis.**

Dear Deborah

I am pleased to advise that the Auckland University of Technology Ethics Committee (AUTECH) approved your ethics application at their meeting on 8 December 2008. Your application is now approved for a period of three years until 8 December 2011.

AUTECH noted the delay in submitting this application and advises that external ethics committee approvals need to be submitted to AUTECH before research commences.

I advise that as part of the ethics approval process, you are required to submit to AUTECH the following:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/about/ethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 8 December 2011;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/about/ethics>. This report is to be submitted either when the approval expires on 8 December 2011 or on completion of the project, whichever comes sooner;

It is a condition of approval that AUTECH is notified of any adverse events or if the research does not commence. AUTECH approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are reminded that, as applicant, you are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

Please note that AUTECH grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to make the arrangements necessary to obtain this. Also, if your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply within that jurisdiction.

When communicating with us about this application, we ask that you use the application number and study title to enable us to provide you with prompt service. Should you have any further enquiries regarding this matter, you are welcome to contact Charles Grinter, Ethics Coordinator, by email at [charles.grinter@aut.ac.nz](mailto:charles.grinter@aut.ac.nz) or by telephone on 921 9999 at extension 8860.

On behalf of the AUTECH and myself, I wish you success with your research and look forward to reading about it in your reports.

Yours sincerely



**Madeline Banda**  
**Executive Secretary**  
**Auckland University of Technology Ethics Committee**

Cc: Linley Stevenson

# Participant Information Sheet



**Date Information Sheet Produced: 11-03-08**

For women who are currently receiving services from the XX Breast Clinic, XX, Auckland.

**Project Title:**

*New Zealand Health Professionals' and Patients' Constructions of Breast Cancer: A Discourse Analysis*

***An Invitation***

My name is Linley Stevenson and I am a psychologist who has worked in the public sector since 1989. I am currently undertaking doctoral studies. My research involves a study of women who have recently had breast cancer, and also health professionals who are involved in the provision of breast cancer treatment and care.

I am inviting women who are over the age of 18 years and who have completed breast cancer treatment within the last 12 months to take part in my study.

Your participation in this study is voluntary, and you can choose not to take part or to withdraw at any stage.

***What is the purpose of this research?***

There has been a large amount of research conducted into women's experiences of breast cancer. However there has been much less investigation into how breast cancer is perceived by society and by the way it is spoken and written about. Therefore the main purpose of this study is to identify and analyse the ways in which women and health professionals think and talk about their experience of breast cancer and its treatment.

***How was I chosen for this invitation?***

The XX Clinic, XX, Auckland has identified you as being a possible participant and has given you this Participant Information Sheet on my behalf. As mentioned above, your involvement in this study is voluntary. You have the right to refuse to take part or to withdraw at any time.

***What will happen in this research?***

If you choose to take part, you will be asked to have a face-to-face interview with me at a time and place convenient to you. The interview will take no longer than 90 minutes. I will ask you to describe your experiences of having breast cancer, and to talk about the care and treatment you received. With your permission the interview will be tape-recorded. The interviews will be transcribed by a typist who has signed a Confidentiality Agreement Form. You will be given a copy of the transcript to read and verify.

***What are the discomforts and risks?***

You may find that taking part in the interview could bring up events that were upsetting for you, and you may find answering some of the questions difficult due to their sensitive nature.

If you choose to participate and become upset recalling events, you may request the interview to be either ended at this time, or stopped and then resumed at a later time. If you would like to seek further advice or support regarding your past experiences please let me know so that I am able to refer you to other agencies as appropriate.

The interview may trigger thoughts and feelings about patients or past events that were upsetting for you. If this happens you may request that the interview be ended at this time, or stopped and then resumed at a later date.

**How will these discomforts and risks be alleviated?**

I am a trained and experienced psychologist and will be watching for any signs of distress you may show during the time that I am interviewing you. If the interview has caused you distress, and you live in Auckland, you may be eligible to access free counselling sessions at the AUT Health and Counselling Service. If you live outside of Auckland, you may be eligible to access free counselling sessions at a counselling service in your local area. You may also phone other local services, such as your local disability support organisation or the Health and Disability Advocate (Phone 0800-555-050). If you wish, I can give you a list of possible contacts.

*What are the benefits?*

I do not anticipate that there will be direct benefits for you if you choose to participate. It may be however, that you will enjoy the opportunity to talk openly and to share your experiences. However, the information gained from this study will help to identify physical, emotional and social issues faced by women who have experienced breast cancer, and of the issues faced by health professionals involved in the provision of breast cancer treatment and care.

The findings of this study will be reported back to the XX Breast Clinic, presented at breast cancer and other conferences and published in relevant professional journals. The findings could also have implications for the development of future strategies, health professional training, intervention and policy.

*How will my privacy be protected?*

You will be asked to give another name that you will be known by during the interview, on the transcripts, in the thesis, and in any publications or conference presentations that may be produced from the study's findings.

Only the researcher and the transcriber will have access to your interview tapes and transcripts. All copies of these will be kept in a locked filing cabinet for ten years. After this time they will be destroyed.

Any material that may identify you or the health professionals who cared for you will be deleted from the transcript.

*What are the costs of participating in this research?*

I do not anticipate any costs other than your time. At the most this will be 90 minutes.

*What opportunity do I have to consider this invitation?*

You will have up to two weeks to consider this invitation. If you choose to take part you should contact the XX Clinic to give your verbal consent for the researcher to contact you, or you can contact me directly. If you have not contacted the XX Breast Clinic or me by the end of the two weeks it will be assumed that you have decided not to take part, and no further contact with you about the study will be made.

*How do I agree to participate in this research?*

If you decide to take part, please contact XX (Breast Nurse Specialist) at the XX Breast Clinic, XX, Auckland, ph XX). XX is co-ordinating the recruitment of participants for this study. Before the interview begins I will talk through the informed consent process with you and you will be asked to sign a Consent Form.

*Will I receive feedback on the results of this research?*

All participants will receive a summary of the research findings. If you request, you will be given a copy of the report.

*What do I do if I have concerns about this research?*

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisors:

Dr Debbie Payne

[debbie.payne@aut.ac.nz](mailto:debbie.payne@aut.ac.nz)

(09) 921 9999 ext 7112

or

Dr Kerry Gibson

[K.L.Gibson@massey.ac.nz](mailto:K.L.Gibson@massey.ac.nz)

(09) 414 0800 ext 41241

You can also contact the Nationwide Health and Disability Consumer Advocacy Service,

Telephone: 0800 555 050

Email: [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTECH, Madeline Banda, [madeline.banda@aut.ac.nz](mailto:madeline.banda@aut.ac.nz), ph 921 9999 ext 8044.

*Whom do I contact for further information about this research?*

**Researcher Contact Details:**

Linley Stevenson: [XX@xtra.co.nz](mailto:XX@xtra.co.nz) ph XX

(This study was given approval by the Health and Disability Ethics Committee on 8 May 2008; **Ethics ref: NTY/08/01/007**)

# Participant Information Sheet



Date Information Sheet Produced: 11-03-08

For health professionals who are currently providing services to clients of the XX Breast Clinic, XX, Auckland.

## Project Title:

*New Zealand Health Professionals' and Patients' Constructions of Breast Cancer: A Discourse Analysis*

### *An Invitation*

My name is Linley Stevenson and I am a psychologist who has worked in the public sector since 1989. I am currently undertaking doctoral studies. My research involves a study of women who have recently had breast cancer, and also health professionals who are involved in the provision of breast cancer treatment and care.

I am inviting health professionals who provide treatment or health care for women with breast cancer to take part in my study.

Your participation in this study is voluntary, and you can choose not to take part or to withdraw at any stage.

### *What is the purpose of this research?*

There has been a large amount of research conducted into women's experiences of breast cancer. However there has been much less investigation into how breast cancer is perceived by society by the ways in which it is spoken and written about. More significantly, there has been even less research into health professionals' perspectives about breast cancer. Therefore, the main purpose of this study is to identify and analyse the ways in which women and health professionals think and talk about their experience of breast cancer and its treatment.

### *How was I chosen for this invitation?*

The XX Breast Clinic, Epsom, Auckland has identified you as being a possible participant and has given you this Participant Information Sheet on my behalf. As mentioned above, your involvement in this study is voluntary. You have the right to refuse to take part or to withdraw at any time.

### *What will happen in this research?*

If you choose to take part, you will be asked to have a face-to-face interview with me at a time and place convenient to you. The interview will take no longer than 90 minutes. I will ask you to describe your experiences of providing treatment and/or care to women with breast cancer.

With your permission the interview will be tape-recorded. The interviews will be transcribed by a typist who has signed a Confidentiality Agreement Form. You will be given a copy of the transcript to read and verify.

### *What are the discomforts and risks?*

The interview may trigger thoughts and feelings about patients or past events that were upsetting for you. If this happens you may request that the interview be ended at this time, or continued at a later date.



**How will these discomforts and risks be alleviated?**

I am a trained and experienced psychologist and will be watching for any signs of distress you may show during the time that I am interviewing you. If this occurs I will suggest that the interview be ended. It is possible that by participating in this study you may experience some feelings of discomfort or anxiety. If this happens either during the interview or afterwards I am able to give you the contact details of the AUT Health and Counselling Service and other relevant counselling or support agencies.

*What are the benefits?*

I do not anticipate that there will be direct benefits for you as a health professional if you choose to participate. It may be however, that you will enjoy the opportunity to talk openly about your experiences. I hope that the findings of this study will provide useful information for breast cancer patients and the health professionals involved in their care. The findings of will be reported back to the XX Breast Clinic, presented at breast cancer and other conferences and published in relevant professional journals, and could have implications for health professional training, intervention and policy.

*How will my privacy be protected?*

You will be asked to give another name that you will be known by during the interview, on the transcripts, in the thesis, and in any publications or conference presentations that may be produced from the study's findings.

Only the researcher and the transcriber will have access to your interview tapes and transcripts. All copies of these will be kept in a locked filing cabinet for ten years. After this time they will be destroyed.

Any material that may identify you will be deleted from the transcript.

*What are the costs of participating in this research?*

I do not anticipate any costs other than your time. At the most this will be 90 minutes.

*What opportunity do I have to consider this invitation?*

You will have up to two weeks to consider this invitation. If you choose to take part you should contact the XX Breast Clinic to give your verbal consent for the researcher to contact you, or you can contact me directly. If you have not contacted the XX Breast Clinic or me by the end of the two weeks it will be assumed that you have decided not to take part, and no further contact with you about the study will be made.

*How do I agree to participate in this research?*

If you decide to take part, please contact XX (Breast Nurse Specialist) at the XX Breast Clinic, XX, Auckland, ph XX. XX is co-ordinating the recruitment of participants for this study. Before the interview begins I will talk through the informed consent process with you and you will be asked to sign a Consent Form.

*Will I receive feedback on the results of this research?*

All participants will receive a summary of the research findings. If you request, you will be given a copy of the report.

*What do I do if I have concerns about this research?*

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisors:

Dr Debbie Payne

[debbie.payne@aut.ac.nz](mailto:debbie.payne@aut.ac.nz)



(09) 921 9999 ext 7112

or

Dr Kerry Gibson

[K.L.Gibson@massey.ac.nz](mailto:K.L.Gibson@massey.ac.nz)

(09) 414 0800 ext 41241

You can also contact the Nationwide Health and Disability Consumer Advocacy Service,

Telephone: 0800 555 050

Email: [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTC, Madeline Banda, [madeline.banda@aut.ac.nz](mailto:madeline.banda@aut.ac.nz), ph 921 9999 ext 8044.

*Whom do I contact for further information about this research?*

**Researcher Contact Details:**

Linley Stevenson: [XX@xtra.co.nz](mailto:XX@xtra.co.nz)

(This study was given approval by the Health and Disability Ethics Committee on 8 May 2008; **Ethics ref: NTY/08/01/007**)

## Appendix E: AUT Consent Form

### Consent Form



*Project title: New Zealand Health Professionals' and Patients' Constructions of the Experience of Breast Cancer: A Discourse Analysis*

*Project Supervisors: Dr Debbie Payne and Dr Kerry Gibson*

*Researcher: Linley Stevenson*

- ☐ I have read and understood the information provided about this research project in the Information Sheet dated 22 November 2007.
- ☐ I have had an opportunity to ask questions and to have them answered.
- ☐ I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- ☐ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
- ☐ If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.
- ☐ I agree to take part in this research.
- ☐ I wish to receive a copy of the report from the research (please tick one): Yes ☐ No ☐

Participant's signature: .....

Participant's name: .....

Participant's Contact Details (if appropriate):

.....  
.....  
.....  
.....

Date:

***Approved by the Northern Y Regional Health and Disability Ethics Committee on 8 May 2008. Ethics Reference number: NTY/08/01/007***

*Note: The Participant should retain a copy of this form.*

This version was last edited on 29 March 2007

## Appendix F: AUT Confidentiality Agreement

### Confidentiality Agreement



*Project title: New Zealand Health Professionals' and Patients' Constructions of the Experience of Breast Cancer: A Discourse Analysis*

*Project Supervisors: Dr Debbie Payne & Dr Kerry Gibson*

*Researcher: Linley Stevenson*

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- ☐ I understand that all the material I will be asked to transcribe is confidential.
- ☐ I understand that the contents of the tapes or recordings can only be discussed with the researchers.
- ☐ I will not keep any copies of the transcripts nor allow third parties access to them.

Transcriber's signature: .....

Transcriber's name: XX

Transcriber's Contact Details (if appropriate):

.....ph: XX.....

Date: 25 November 2007

Project Supervisor's Contact Details (if appropriate):

Dr Debbie Payne

Dr Kerry Gibson

Email: [debbie.payne@aut.ac.nz](mailto:debbie.payne@aut.ac.nz)

Email: [K.L.Gibson@massey.ac.nz](mailto:K.L.Gibson@massey.ac.nz)

Phone: (09) 912 9999 Ext 7112

Phone: (09) 414 0800 ext 41241

.....  
.....

***Approved by the Auckland University of Technology Ethics Committee on 8 May 2008.***

***AUTEC Reference number 08/284***

*Note: The Transcriber should retain a copy of this form.*

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Student ID No	0657550	Name	Linley Stevenson
Faculty	Health and Environmental Studies	School/Dept	Centre for Midwifery & Women's Health Research
Programme	PhD	Year of submission (for examination)	2014
Research Output	Thesis <input checked="" type="checkbox"/> Exegesis <input type="checkbox"/> Dissertation <input type="checkbox"/>	Points Value	360
Thesis Title	Anxious Times: A Discourse Analysis of Women's and Health Professionals' Constructions of the Experience of Breast Cancer		

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Student's Signature

*LE Stevenson*

Date

*25 February 2015*