MAKING SENSE OF BREAST CANCER:

A NARRATIVE STUDY

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ABSTRACT
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MAKING SENSE OF BREAST CANCER: A NARRATIVE STUDY

**Background and objectives:** Despite an abundance of research in the field of psycho-oncology, there is little that has come from the discipline of counselling psychology placing importance on social justice-oriented work of 'giving voice' (by providing a space for storytelling) and 'consciousness raising'. This study explores the experience of breast cancer by generating and analysing individual stories of women with breast cancer. The wider objective of this research is to enhance psychological support offered to women with breast cancer through embracing the process of meaning-making. **Method and analysis:** Adopting a narrative framework, an unstructured narrative encounter took place with four women at varying stages of breast cancer. The transcribed oral stories told by each woman were then restored into a prose account. The final restored version was then analysed using a narrative analysis. This approach allowed me to critically investigate and interpret the construction of meaning within each story, using language to bring light to unique aspects of the experience of breast cancer. **Analysis:** By examining the narratives of four women, the diversity of experience was made apparent. The transformations that took place were varied and non-linear, with the stories oscillating between different ‘narrative types’ (Frank, 1995). Analysis focused on how metaphor was used to express contradictory meanings and concepts that might otherwise be difficult to express. In conjunction with the analysis, I reflexively analysed my own theoretical and philosophical standpoint, making transparent the context in which I carried out the research. **Conclusion:** The insights gained from this research have the potential to extend our understanding of what counselling psychology could offer the field of psycho-oncology. The stories highlight the importance for practitioners to encourage encountering of suffering, and offer a space in which existential questions that have no answer can be explored. There needs to be sensitivity to the complex meanings that are made when forming a coherent story, and adjusting to the appearance of breast cancer. **Key Words:** Narrative, breast cancer, counselling psychology.
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INTRODUCTION

This thesis provides a report on a study of four women's experience of breast cancer, asking them to tell me their stories of cancer and reflect upon their experiences. Over the course of this thesis, I will hope to develop a theoretical framework from which to answer the following questions:

- What insights do women's narratives provide regarding how they make meaning from their experiences of breast cancer?

- What implications might there be from such insights for counselling psychology?

This thesis developed from a placement at a large leading cancer hospital as a professional placement as part of my counselling psychology doctorate, a placement in which I offered individual psychological therapy to patients and their families.

This thesis begins with an introduction to the genesis of the study, through personal, practical and social justification as to the relevance of this study as a doctoral study for a counselling psychologist trainee (Chapter 1). Chapter 2 uses the relevant literature to conceptualise the study, and, building on this foundation, I outline my methodology. In Chapter 4 I situate and then present the narratives generated for and through the study, and in Chapter 5, using narrative analysis, I offer an interpretation of these narratives. In this chapter, I also offer a discussion of the use of metaphor, an aspect that arose when reading across the stories. In Chapter 6, I make transparent my own theoretical and philosophical standpoint as a counselling psychologist, as someone choosing to research in the field of psycho-oncology, and as a woman carrying out research with other women. Chapter 7 discusses the study as a whole, in the context of a counselling psychology doctorate, reflecting on what implications there might be for the field of counselling psychology from insights gained in this study. Finally in Chapter 8, I will summarise the purpose of the study, discuss potential limitations and future considerations, and summarise the insights gained from the study.
Chapter 1

The Genesis Of The Study

"As wounded, people may be cared for, but as storytellers, they care for others. The ill, and all those who suffer, can also be healers...Through their stories, the ill create empathic bonds between themselves and their listeners." (Frank, 1995: xii).

1.1 Introduction

This thesis presents the stories of four women with breast cancer, and reflects on the potential insights that these stories provide regarding how these women make meaning from their experiences of breast cancer. As the above quote reflects, there is power in presenting ill people as storytellers, and in doing so, there is potential for their voices to be heard against a dominant medical backdrop. I will endeavour to relate the emancipatory aims of this study with the principles of counselling psychology.

The study stemmed from my personal confrontation, when working at a cancer hospital, hearing the stories told by those affected by cancer. Recognising the importance of positioning myself as the researcher, I will explain to the reader the journey I took into this research, offering a justification of the research in the context of counselling psychology. This will be discussed in terms of personal, practical and social terms, three dimensions outlined by Clandinin and Huber (2010) as the most salient design considerations for a narrative inquiry. This is based on the view that, as narrative inquirers, our lived and told stories are always in relation to, or with, those of our participants. We are part of the stories that we present, and thus, it is important to state the way in which our chosen study of interest first transpired. In order to achieve this, I begin by writing myself into the inquiry and valuing subjectivity.
1.2 Justification

1.2.1 Personal Justification

The motivation behind this study stems from a placement at a cancer hospital during the first and second year of my training as a counselling psychologist. As a trainee, I became aware of the fact that the environment I was in was one whereby Cognitive Behavioural Therapy was, and still is, promoted as the treatment of choice in the United Kingdom (Merret & Easton, 2008). Moreover, traditional methods of research conforming to the medical model of classifying patients according to emotional reactions have resulted in the production of statistical data regarding the 'problems' of cancer patients (Mathieson & Stam, 1995). Such a stance is likely to implicate diagnoses such as depression and anxiety which often may appear on the surface as a result of a diagnosis of cancer. In fact, the complexity of each individual experience was evident in the therapeutic work I undertook, suggesting a discrepancy between classifying patients and the idiosyncrasies of individual experience. For instance, when referring to psychological therapies for cancer patients, one of the more extensive and rigorous literature reviews conducted in this area referred to intervention strategies, and statistically significant benefits of such strategies (Newell et al, 2002). Such an approach to working therapeutically is not fitting with the humanistic philosophy upon which I base my own work. A changing sense of self (Clarke et al, 2010) often appeared to be at the forefront of the therapeutic work that I was carrying out with these clients, an aspect of therapy that I struggled to encounter when relying purely on the research related to randomised, controlled trials reviewed by Newell et al (2002). With each person I met, I heard a desire to tell a story. This was met by my desire to create a space in which they could tell diverse stories from which they could develop, rather than attempt to shape them by the narrow plotlines that are often presented in empirical, evidence-based research. I was, therefore, left questioning what we as counselling psychologists could do to open up the available narratives that are offered to patients with cancer.

My interest in the meaning-making process of women with breast cancer, and the way in which identity is shaped and constructed stems from a dissatisfaction with clinical approaches that take a stance of the "knowing one" (Gergen & Gergen, 2008: 179). As I have travelled through the training process, my urge for sure-mindedness has deflated, and I have moved from the well-formed psychological theories discussed in undergraduate psychology, to a reflexive stance more appropriate to the narrative study of identity.
transformations and meaning-making processes that can occur following an existential crisis. I will discuss below the link between this personal interest in meaning-making, and how it relates to counselling psychology. Moreover, in Chapter 6, I will return once again to an exploration of my own personal stance in relation to the present study.

1.2.2 Practical Justification

In terms of practically justifying this study, I ask myself how such stories may be insightful in the field of counselling psychology for changing and thinking differently about our practice. Counselling psychology as a practice bases its philosophy in a set of humanistic values and ethics (Kanellakis, 2009). According to Packard (2009) there are nine core values that form the basis for the discipline of counselling psychology:

1. Altruism is our foundation as we strive to enhance the welfare of others.
2. Positive relationships are a necessary condition for stimulating change in those we seek to help.
3. The synergistic integration of science and practice is essential to our work and includes the use of various methods of inquiry.
4. We focus on healthy development across the life span, including work and career, and seek to prevent avoidable problems as well as optimise individual and societal growth.
5. From a holistic frame of reference, we emphasise strengths, resilience, and positive coping in the context of the person's social and cultural environments.
6. We are committed to respectful treatment for all, inherent human dignity, inclusion rather than exclusion, and accepting and celebrating cultural and individual diversity.
7. We believe in social justice and the necessity, on occasion, of advocacy for just causes that promote the welfare of others.
8. We value collaboration, multidisciplinary practice and research, and sharing counselling psychology with colleagues in our own country and around the world.
9. In our remedial work with dysfunctional clients and systems, whenever possible we focus on strengths and positive coping in the context of a helping relationship. (Packard, 2009: 623).

As noted by Packard, social justice is one of the core values of counselling psychology. Consequently, an emancipatory approach to the profession is compatible, whereby a helping relationship is used therapeutically to focus on giving voice and liberating a client from their life context. The unique context that shapes an individual's life, and the
potential impact on their mental health and well-being, is something that I believe ought to be acknowledged in the fields of counselling and psychotherapy. I believe that by adopting these values, there is potential to contribute more to the understanding of women's experience of breast cancer.

No two patients with cancer show exactly the same emotional response, with the individual perception of the threat of cancer being determined by the characteristics of the person concerned (Holland, 2002). As a trainee counselling psychologist working in the context of a cancer hospital, I was aware that often there was very little space to attend in depth to the underlying story that shapes a person's character. Instead there is perhaps a tendency to turn towards intervention strategies, of a generalised and manualised nature, employed to cope with cancer. My practical justification, therefore, arose from an eagerness to explore the possibilities that might be created when integrating the principles of counselling psychology in the field of psycho-oncology. McDermott et al (2006) posit that written narratives provide an opportunity for professionals to make sense of experiences of illness, therefore drawing my attention to the important contributions that counselling psychology could offer as an alternative stance toward psycho-oncology, with a focus on the emancipatory and voice giving aims of narrative research.

1.2.3 Social Justification

Cancer in our current society is more often being experienced as an intermittent chronic condition, as patients encounter repeated episodes of reoccurrence and treatment. Therefore, the division between wellness and sickness has become blurred in postmodern times, as the 'remission society' is becoming a significant aspect of the society in which we live (Frank, 1995), as advanced medicine makes ongoing survival possible. Frank (1995) adapts Susan Sontag's (1978) metaphor of illness as travel between the kingdom of the well and the kingdom of the sick. He posits that members of the ‘remission society’ do not in fact belong to either place, and are therefore left kingdom-less, resulting in considerable ambivalence in how people construct their position socially as an ill person (Payne & Seymour, 2008).

Sociological and anthropological literature has long placed a focus on the impact of illness and continual contact with health care services on an individual's personal identity (Kleinman, 1980; Helman, 2000). The label of 'patient' is still a dominant one in health care settings, differentiating the 'ill' from the 'well' (Payne & Seymour, 2008), and I wonder what implications this has on the identity of women who have experienced breast cancer. If the field of counselling psychology turns its focus to hearing the stories of
women who have experienced a cancer diagnosis, there is the potential to emancipate these individuals from the traditional labels of patient and sick person, therefore opening the way for new narratives to be heard and offered. With life threatening illness implying limited possibilities and a transition from activity to passivity, a focus on storytelling in a therapeutic setting may encourage a more active and empowered response to cancer, by forming a social position for women with illness. This kind of dialogue has the potential to at least begin to generate more discourse.

By hearing the stories of women with breast cancer, my goal was to challenge prevailing assumptions, such as beliefs that the primary concern for women is 'appearance', a view that has infused much of psycho-oncology literature in the past (e.g. Derogatis, 1980; Holland & Mastrovito, 1980). Based on assumptions that after lumpectomy or mastectomy, women's major concerns are anxieties around appearance, literature encourages facilitating 'adjustment' by encouraging women to feel feminine. Such words as 'adjustment' are common terms in psychotherapy, and I would posit that as counselling psychologists working in psycho-oncology, it is our responsibility to think beyond adjustment, and consider body-self connections in holistic terms. In fact, in a study of 112 breast cancer patients, 'future health' was cited far more frequently as an important concern than physical attractiveness (Meyerowitz, 1981). The opportunity to further challenge conclusions based on social stereotypes and sexist bias, along with the hope to provide a space for women to give their own account, I feel is fitting with the humanistic philosophy of counselling psychology and its therapeutic approach of focusing on each client's subjective experiencing of what is happening (Kvale, 1992). Therefore, I hope to take an approach to research that offers an opportunity to make women's experience visible, reclaiming this as central to the research (Wilkinson, 2000).

1.3 Conclusion

In this chapter I hoped to make clear to the reader my journey to this study. Taking into account the above justification, and building upon my reflections, my intention is to address the following research questions:

- **What insights do women's narratives provide regarding how they make meaning from their experiences of breast cancer?**

- **What implications might there be from such insights for counselling psychology?**
In order to answer these research questions, I needed to position the subjective as legitimate in the research of human experiences (Moustakas, 1990). Moreover, by moving away from the sense of power that might be gained from the belief in a measurable reality, my hope is to approach the above research questions from a stance that reduces the barrier between the research and researched (Etherington, 2004). In the following thesis therefore, I will aim to be transparent about my values and beliefs, and take responsibility for my views, by using the first person pronoun, 'I' (ibid). With these questions in mind, in Chapter 2 I will turn to the conceptualisation of this research, grounding it in existing research.
Chapter 2

Conceptualisation of the Study

organisation of Chapter 2

Introduction
Rationale for the research
Rationale for a narrative inquiry
Conclusion

2.1 Introduction

This chapter conceptualises the study of women's narratives when faced with illness. Parker (2004) identifies the importance of grounding qualitative research in existing literature, an overarching criteria for 'good' research. It is with this in mind that I focus this chapter on identifying existing lines of research around the issues being studied, forming a foundation for this study. My hope in this study is to enrich what is already known, rather than highlight gaps in the existing literature.

There are two main sections at the core of this chapter, followed by a conclusion. The first section forms a framework for the rationale of this research, beginning with an overview of the psychology of illness and more specifically of traditions of psycho-oncology research. With the tendency for such research to produce large scale, quantitative results, classifying patients according to emotional reactions, I turn to feminist research as an alternative, whereby individual and personal experiences may be heard. I therefore scope feminist literature of women's experience of breast cancer, from which I hope to build upon. The second section introduces Bruner's (1990) narrative mode of thought, as a rationale for using a narrative inquiry approach to this study. I will conclude with a discussion of making meaning through stories, relating it specifically to research into women's stories of breast cancer.

This review brings together literature I have encountered over the course of my three year Professional Doctorate in Counselling Psychology. The majority of citations were found via the following electronic databases of journals: PsycInfo; CINAHL Plus (Cumulative Index of Nursing and Allied Health Literature; Google Scholar; and Medline. Additional sources have been found through a method of 'snowballing', whereby the reference lists of identified sources were searched.
2.2 Rationale for the research

In this section I will reflect upon the psychology of illness, considering the approaches used for such research. Initial focus will be on the psychology of illness in general, and then, more specifically, psycho-oncology. The intention is to set a foundation for illness as a psychological event, not simply as a physical experience. I will then bring the reader's awareness to the concerns and findings of feminist research, and the implication of these concerns on the field of psycho-oncology.

2.2.1 The psychology of illness

2.2.1.1 What illness means to the individual

The experience of illness was first classified by Sydney Smith in a 1964 Nursing Forum edition not just as a physical experience, but as a psychological event consisting of:

1) those that are related to the meaning that illness has for them; Smith argued that a person with sickness may entertain unconscious fantasies about the meaning of their illness. In relation to this, Janis (1958: cited by Smith, 1964) saw exposure to any stress involving the threat of bodily damage as having the potential to facilitate the revival of disturbing childhood memories. It was, therefore, concluded that health care professionals engage with the patient's ego, and have an awareness of the patient's memories;

2) those that pertain to the threats of illness; Smith argued that it is normal for a patient with an illness to withdraw from the world, and concentrate on his or her body and needs, which has the possibility of regression and dependency on others;

3) those connected with the pain that is related to illness; Smith posited that pain frequently becomes exacerbated when the illness is invested with psychological meaning. Again, Smith saw these reactions in terms of a patient's underlying unconscious fantasies about the personal meaning of illness.

Whilst Smith's (1964) theories were progressive in acknowledging the psychological impact of physical illness, they also reflect a time in which the roles of psychologists and psychiatrists were to diagnose a problem and fix a disorder. Richard Druss (1995), also a medically trained practitioner, identified six common psychologically related problems associated with physical illness: 1) illness as punishment leading to unlovability, 2) illness leading to a state of helplessness, 3) illness involving a sense of betrayal, 4) illness causing
changes in the self, 5) illness becoming a preoccupation, and 6) illness as a cause of loss. Such theories came from a psychodynamic focus on defences, and Druss (1995) in fact acknowledged a need to go beyond such explanations. As a counselling psychologist in training, I start with an assumption that people are active and individual agents engaged in constructing their lives and relationships (Cooper & McLeod, 2011), a view that does not fit comfortably with traditional theories based on unconscious fantasies and psychological defences.

A more recent psychological theory of responses to illness, whilst not revealing the idiosyncrasies of the unique meaning-making of individuals, perhaps opens up our understanding of the illness experience, moving away from a view of diagnosis and cure of the psychological issues related to illness.

Historically, the understanding of the trauma of illness has been oriented toward psychological suffering (Joseph, 2011), originating with Sigmund Freud, a medical doctor, influenced by medicine, disorder and cure (see Maddux, 2008, for a discussion of the origins of psychology's influence by the medical profession of psychiatry). It was Frankl, in his book *Man's Search for Meaning* (1984/1946), who first began to examine the idea of positive change following adversity. Other psychologists also began to acknowledge and focus on the positives that could psychologically arise from misfortune. For instance, Abraham Maslow (1955: cited by Joseph, 2011), saw experiences such as tragedies, deaths and other traumas as forcing people to take new perspectives in life. Similarly, existential psychologist Irvin Yalom (2008) wrote about meaning in life arising through confrontation with death, causing an individual to question how they live their life.

In relation to gaining meaning from trauma, the area of positive psychology is worth mentioning briefly. Whilst the scope of this thesis does not allow for an in-depth discussion of positive psychology, I will reflect upon its relevance to the psychology of illness. Its original goal was to acknowledge life as consisting of ups and downs, negatives and positives, and consequently psychological research ought to focus not just on the negatives, but also what makes for a good life (Joseph, 2011). Consequently, the study of well-being determines how it can be achieved despite physical illness. What the term 'well-being' actually means is something of contention, with one definition being the absence of negative states of mind. However, positive psychologists asserted that well-being was also the presence of positive states of mind (ibid), which can be understood through the distinction of hedonism and eudaimonism. Whilst hedonism refers to the pursuit of pleasure as the goal of a good life, eudaimonism views well-being in terms of a
life dedicated to seeking meaning, engagement with existential challenges of life, and the actualisation of human potential (see Ryan, Huta & Deci, 2008, for a distinction between hedonic and eudaimonic well-being), all associated with post-traumatic growth and better long-term mental health. Counsellors and psychotherapists working therapeutically with people with physical illness could potentially focus clients on eudaimonic well-being, as achievable despite illness. Of relevance to the above psychological understanding of illness, studies carried out with individuals with physical injuries or illness (e.g. Manne et al, 2004; Powell et al, 2007: cited by Joseph, 2011), show the general pattern of posttraumatic growth seeming to emerge gradually over time (Joseph, 2011).

The notion of growth following adversity therefore has implications for those working therapeutically with individuals with physical illness. However, much of the research has been carried out using large scale, quantitative studies, which, although acknowledges the potential of growth following traumatic events, is lacking subjective perspectives. This is of relevance to the rationale of this current study and will be discussed in more depth below. However, I will first consider how the field of psycho-oncology approaches research aimed at improving the psychological care of patients.

2.2.1.2 Psycho-oncology; can CBT meet the needs of cancer patients?

As with other physical illness, cancer is also a psychological event, as a disease that has been feared beyond all others for centuries (Holland, 2002). Psycho-oncology, a sub-speciality of cancer has been defined as:

"dealing with two psychological dimensions: the psychological reactions of patients at all stages of their cancer illness and the stresses on their families and clinical staff; and studies of the psychological, social, and behavioural factors that contribute to cancer cause and survival."

(Holland, 2003: 259).

Holland (2003) recognises this field of care as beginning formally around the mid 1970's, when a greater sense of optimism about cancer increased discussions around a patient's cancer diagnosis and the implications for their lives. Research emphasis within psycho-oncology has tended towards quantitatively measuring symptoms such as pain, anxiety and depression, with Shipper et al (1984) developing a quality-of-life (QoL) scale that was later validated by health psychologists as an outcome measure in cancer clinical trials. The aim was to classify patients according to their emotional reactions to cancer, adapted from the medical model of diagnosis and treatment. This however can be problematic when
conclusions are made which resemble those about mentally ill populations, thus treating cancer patients for a psychopathological diagnosis (Mathieson & Stam, 1995).

Within cancer research, much of the psychosocial literature focuses on 'adjustment', using standardised questionnaire measures, such as the Hospital Anxiety and Depression Score (HADS), to assess quality of life in cancer patients (Crossley, 1998) and to propose interventions to reduce anxiety and depression. In a review of studies on the effects of psychological treatment on cancer patients, Trijsburg et al (1992) found that goals of psychological therapy consisted of global objectives such as enhancing quality of life, facilitating adjustment, reducing levels of distress and anxiety, and increasing effective coping strategies.

CBT is one form of psychotherapy that, based on evidence-based support, is used to treat issues such as distress, pain and anxiety in cancer patients (e.g. see Tatrow & Montgomery's meta-analysis, 2006). For people who struggle to find the appropriate coping strategies when faced with a cancer diagnosis, a therapist using CBT could help facilitate identifying new thinking patterns to monitor and manage distressing emotional responses. Antoni et al (2006) examined a cognitive behavioural stress management programme for women with breast cancer and found that, on average, those who were initially less optimistic appeared to benefit the most, reporting less depression. One possible implication for such findings was posited by Joseph (2011), who suggested that those who need to increase their repertoire of coping skills for dealing with emotional reactions to cancer will benefit most from such training. Such research frameworks however, have some shortfalls, many of which rest upon its scientific, evidence-base, relying on quantitative measures. Empirically supported approaches to therapy are based on an assumption that most clients either have, or can be treated as if they have, one primary syndrome, for which a single treatment can be designed (Yalom, 2002). This fails to acknowledge the complexities and subjectivity of the experience of cancer, therefore reinforcing the medical model of intervention in the field of psycho-oncology (Hemsley, 2010). Moreover, Pitchford (2009) reflected that advocating CBT for a trauma such as cancer has the potential to focus treatment only narrowly on symptom management. As stated by Shainberg (1983), therapists who introduce active interventions and cognitive strategies as a means of reducing a client’ anxiety about cancer may as a result "drown their empathy or appreciation of the patient's struggle" (p.164), consequently leaving little room for meaning-making. Therefore, whilst therapeutic work informed by CBT principles may always have a place in psycho-oncology, it could be posited that at times
such techniques might become barriers for what is really going on. What such psychological research lacks is theory based on actual experience.

Another specific field of psychology research that has implications for psycho-oncology, is the new psychology of posttraumatic growth (Joseph, 2011). As discussed above, such research has found support for the potential of transformation and growth following a traumatic event such as cancer. However, again much of the research is quantitative and large-scale, and I question how we can reclaim and validate women's experiences alongside such research. Transformation is an important thing to consider, but to hear of the experience through the voices of individual women is an aspect that ought not to be ignored. I will, therefore, discuss below breast cancer in the context of feminist research concerns, respecting and embracing individual diversity and the subjectivity of human experience (Packard, 2009).

2.2.2 Breast cancer

2.2.2.1 Contextualising breast cancer

Before moving on to discuss feminist research and breast cancer, I will first contextualise breast cancer, outlining potential risk factors, diagnosis, different stages of breast cancer, and the difference between primary and secondary breast cancer. It is hoped that by contextualising in this way, the disease being discussed throughout this thesis is made clear, and the stories presented in Chapter 4 will have a more contextual meaning to the reader. Breast cancer is the top cancer in women in both the developed and the developing world, with the incidence of diagnosis increasing in the developing world due to the increase in life expectancy, increased urbanisation and the adoption of western lifestyles (WHO, 2008). Breast cancer survival rates vary greatly worldwide, ranging from 80% or over in North America, Sweden and Japan, to around 60% in middle-income countries and below 40% in low-income countries (Coleman et al, 2008). The difference in breast cancer incidence between developed and developing countries can be partly explained by dietary effects combined with later childbirth, lower parity and shorter breastfeeding (Peto, 2001). The increasing adaptation of western life-style in low income and middle income countries is an important determinant in increases of breast cancer incidence in these countries. For the majority of women with breast cancer, it is not possible to identify specific risk factors (Lacey et al, 2009). A familial history of breast cancer increases the risk by two or three factors. Whilst some mutations result in a very high risk of breast cancer (these mutations include BRCA1, BRCA2, p53), these mutations are rare and account for a small proportion of cases.
Breast cancer screening is the way in which cancer is looked for before a person has any symptoms, with the most common form of screening being a mammogram. Breast cancer occurs when there are tumours, or groups of cells clumped together, in breast tissue. The original cancer in the breast is known as a primary breast cancer. In some cases, cells may break away and spread to another part of the body and form a new tumour. This is called a metastasis or a secondary cancer. Although the cancer has spread to another part of the body, the secondary cancer is made of breast cancer cells. The symptoms of secondary breast cancer depend on which part of the body the breast cancer has spread to.

The main treatments for breast cancer are surgery, radiotherapy, chemotherapy, hormone therapy or biological therapy, all of which may be used in isolation, or in combination. When a person has secondary cancer, it is not curable, and treatment is therefore aimed to achieve remission.

2.2.2 Feminist research and breast cancer

"Breast cancer is a disease which both threatens a woman's life and disrupts her physical integrity as a woman, often in starkly visible ways...breast cancer is not only a health crisis but, a crisis which could end in death or, at best, a violation of her understanding of herself as a woman" (Kasper, 1994: 264).

Whilst the research discussed thus far plays a part in understanding the experience of cancer, what it often seems to lack is theory grounded in actual experience heard through voices of individuals. Whilst quantitative studies (e.g. Manne et al, 2004) can offer a broad notion about the psychological impact of breast cancer, hearing women's personal experience of breast cancer is lost. From searching the literature, I conclude that the field of psycho-oncology is one that is largely dominated by a medical model, with the language used being related to diagnosis, cure, and treatment. Whilst I was working as a trainee counselling psychologist with people with cancer, I struggled to find literature fitting with the pluralistic framework of openness to an infinitely wide range of ways of engaging with individual clients, rather than a preconceived framework. Research attempting to make universal claims does not fit with such a philosophical stance toward therapeutic work. Moreover, as I reflect on my own social and cultural circumstances that influence the stories I tell (i.e. the narrative I tell of this particular study, and the interpretations I make throughout), I conclude that there is a call for more research forming links between theory and the social experiences of participants. Western culture is one which places high value on breasts as part of femininity and sense of self as a woman. The way in which women with breast cancer might manage this threat to body and self is something that, I feel, as
someone having worked in the field of psycho-oncology, ought to be acknowledged by therapists working in this field.

Feminist research has been a largely unacknowledged part of health psychology such as psycho-oncology (Wilkinson, 2000). Reflecting on this, I consider the values of the discipline of counselling psychology, focusing upon these particular core values: 1) Altruism is our foundation as we strive to enhance the welfare of others; 2) We believe in social justice and the necessity, on occasion, of advocacy for just causes that promote the welfare of others (Packard, 2009: 623). With this in mind, an important area of research is to further emancipate the individual voices of women with breast cancer with the hope to better understand and improve women’s lives (Wilkinson, 2000). It is for this reason that I turn from traditional health psychology and psycho-oncology research to feminist research approaches.

Qualitative in its form, feminist research aims to enable women to be active participants in the research process, with the objective being to explore "how to begin from our own centre, how to begin from our own experience, how to make ourselves as women the subjects of the...act of knowing" (Smith, 1979: 154, cited by Kasper, 1994: 265). It has, therefore, the potential to challenge preconceptions and offer an opportunity to develop new insights. In the context of breast cancer activism, feminist research approaches have been regarded as playing a key role in making visible and collective the ideological issues surrounding this disease (Radley & Bell, 2007). As noted by Klawiter (2004), social movements achieve the most impact "through changing popular images, ideas, emotions and identities" (p.851), with such movements being achieved through feminist research. Radley and Bell (2007) propose artwork as an important form for establishing a sense of solidarity among women with breast cancer. Jo Spence (1988) for example used photography of her breast cancer experience to contest the power of medicine to fragment lived experience, implicating the emancipatory potential of such visual or discursive space. Radley and Bell claim that artwork such as that of Spence and Martha Hall (2003; cited by Radley & Bell, 2007) are of value to health and illness, offering alternative representations of illness, and consequently challenging the dominant medical discourse related to women with breast cancer.

The role of discursive space in representing alternative illness experience has also been explored by Willig (2009). Stacey (1997) identifies a range of functions associated with writing about illness experience, acknowledging the attempt to externalise and gain control. For Willig, writing became a reflexive space in which she engaged with her
cancer experience, helping her to hold onto her own truth, and, if necessary, resist alternative meanings offered. Feminist research therefore can have an emancipatory effect, offering alternatives to dominant medical discourse related to 'survivor' identity. This will be discussed further in sections below.

2.2.2.3 The experience of breast cancer

At the beginning of this chapter, I formed a foundation for this study, by reflecting upon the psychology of illness, and also the field of psycho-oncology. Reading this literature, I was left with a sense of much of the research being impersonal, with no voice of the individual being heard. It is for this reason that I turned to the writings of feminism to further develop the rationale for my study. As can be seen from the above introduction to the feminist research tradition, such research enables us to engage with the diversity of women's subjective experiences of health (Wilkinson, 2000). Moreover, it has the potential to incorporate considerations of social factors such as dimensions of power and inequality (Thomas-MacLean, 2005), an important consideration in the fields of psychology and oncology. For example, the experience of a physical illness and its impact on well-being is not only rooted in psychology or the physical dimension of illness, but also in the social reality of the individual experiencing breast cancer. I will now consider findings that incorporate different aspects of the experience of breast cancer, adding further dimensions to the discussion of psycho-oncology.

i) Relationship with appearance and body

The first thing that stands out from feminist research of the experience of breast cancer is a questioning stance towards assumptions about appearance and preoccupations with transitioning women's appearance quickly back to normality. Traditionally, many studies of the repercussions of breast cancer have relied almost exclusively upon quantitative measures of body image, self-concept and self-esteem, as fitting with the quantitative, empirical stance of psycho-oncology. Numerous quantitative studies report aversive effects of breast cancer on body image (e.g. Derogatis, 1980; Mock, 1993; Penman et al, 1987), despite empirical evidence sometimes being mixed (Langellier & Sullivan, 1998). Qualitative research suggests such clinical breast cancer research is problematic, with Langellier and Sullivan (1998) asserting that such clinical, quantitative research replicates sexist power dynamics, as women speaking for themselves about breast cancer suggest that issues other than breast loss are more important. The emphasis of literature on appearance and remaining feminine can perhaps be understood if we reflect upon social norms, stereotypes and sexist biases as influencing the directions of research (Thomas-MacLean,
Feminist research challenges the assumptions of social norms with Kasper (1994), for example, acknowledging the varying life experiences that women encounter, with the aim of discovering how women distinguish between social expectations and personal beliefs when managing breast cancer. The personal meanings constructed by the women were revealed by Kasper as "deep and complicated" and "embedded in social roles and institutions" (Kasper, 1994: 278). Taking this into account, assumptions that the primary concern of women is about appearance and looking feminine are not so straightforward. Challenges to the assumptions of social norms were further taken up by Langellier and Sullivan (1998) who examined 'breast talk' in women's narratives in order to hear the stories in the words of the women themselves. They found that the women's narratives did not support a primary preoccupation with femininity and sexuality, but were constructed in a way that avoided a reduction of breast cancer to an experience that emphasises cosmetics and beauty culture. Langellier and Sullivan concluded by urging future research to resist objectifying and stereotyping sexist culture, when the experience of the body appears to be embedded in a larger life story.

Wilde (2003) posits that the body exists along various dimensions, including one's physical being and the 'sociological body' (Barral, 1969: cited by Thomas-MacLean, 2005). If we view the experience of breast cancer and living in an altered body both in terms of immediacy and within a specific context, literature suggests a far more complex experience than patriarchal social norms would suggest. In relation to psychological support of women with breast cancer, findings from feminist research discussed brings into question literature that typically recommends facilitation of successful adjustment by encouraging women to 'look feminine' as quickly as possible (Wilkinson, 2000).

ii) The experience of the self

Reflecting on the quantitative studies discussed previously regarding post-traumatic growth and transformations, the focus of the discussion moves onto whether feminist research may add a new dimension to these quantitative findings. Wilkinson (1998) listened to women in focus groups, and found common discussions focused on ways in which breast cancer had changed them, telling stories of identity change and development. Considering the traditional aims of psycho-oncology being to facilitate successful 'adjustment', as discussed in previous sections, Wilkinson goes on to question such a focus.
Her feminist approach to breast cancer research appears to offer new insights into women's experiences, whereby stories are told about whom they are now; who they were; and why and how they made the transformations. Based on this reconceptualisation, Wilkinson suggests that rather than theorise the experience in terms of 'coping strategies', we might better understand it within a framework of identity change and development. These changes might be viewed in terms of the multiple identities and social realities that exist in an individual's life (Klawiter, 2004).

In relation to transformations, various studies, using a qualitative approach, have highlighted certain concepts. In their qualitative meta-synthesis reviewing the lived experience of breast cancer, Arman and Rehnsfeldt (2003) refer to a 'turning point' when women encounter the disease and its consequences. The turning point is associated with an expanded understanding of the self, fitting with Moch's (1990) concepts of 'identifying meaning' and 'an expanding consciousness', as expressed in descriptions of focusing on purpose of life and an awareness of mortality. Arman and Rehnsfeldt (2003) interpret these altering and transforming processes in terms of women facing threats and reconnecting and restoring life. They found that although studies named changes under different concepts, they were all interpreted as paths to regaining integrity, balance and wholeness of the person.

Importantly, these transformations were also denied by a number of breast cancer informants, highlighting the complexity of the phenomena (Arman and Rehnsfeldt, 2003), and the importance of hearing "darker sides of experience, such as women's suffering" (Arman & Rehnsfeldt, 2003: 523). It could be suggested that the tendency for researchers to fragment individual accounts into thematic categories means that the idiosyncrasies of suffering might be lost in favour of themes of change and transformation. A study from Kaiser (2008) appears to offer a warning of any research that encourages embracing any general representation, whether it be in terms of change and transformation, or in the case of this research, the dominant representation of breast cancer survivor. Kaiser used her study to consider the extent to which women embrace the survivor identity following breast cancer treatment. Before discussing this particular study, I will begin with an overview of the dominant image that represents a woman who has had breast cancer.

The breast cancer movement in the 1980's and 1990's consisted of a large and diverse group of women seeking radical changes, urging greater medical investment in the disease (Kaiser, 2008; Klawiter, 1999). Within this movement, the breast cancer survivor represented the power of medicine to beat breast cancer and return women to fulfilling
lives. Klawiter (1999) described the representation of survivors at a leading fundraiser race, 'Susan G.Komen Race for Cure' as "honoured for their courage in fighting breast cancer and for their willingness to demonstrate to other women through their rejection of the cultural code of silence and invisibility" (p.111).

Despite this survivorship image being the dominant one of life after breast cancer, alternative constructs also co-exist. Hozman (2005: cited by Kaiser, 2008) for example, herself a breast cancer survivor, explicitly criticised the upbeat, grateful image of breast cancer survivors. Survivorship has also been criticised for encouraging women to conceal the physical effects of cancer, whereby women are left only with the option to recreate themselves in the image of healthier bodies (Kaiser, 2008), something which Batt (1994) warns of having an emotional price. Whilst the survivorship narrative of diagnosis, treatment and recovery fits with Frank's (1995) description of a 'restitution narrative' (Frank's narrative types will be discussed in more detail below), the uncertainties and chronicity of cancer are lost (see Frank's (1995) discussion of the 'remission society' for a more detailed discussion of this).

Based on these criticisms, Kaiser (2008) attempted to clarify women's relationship to the identity of survivor, and to offer alternative meanings. She found that 'survivor' was rarely spontaneously referred to, although some did embrace certain dominant meanings of survivorship, such as concepts of winning a battle. Many women expressed an incongruity between the survivor identity and the uncertainty often experienced. Kaiser's findings suggest, in fact, that dominant representations of the illness pose challenges for individuals attempting to renegotiate their sense of the world and themselves following breast cancer. In fact, the women in this study reflected upon the fact that truthful stories are more desired than stories focusing on positivity.

Within both subsections, 'relationship with appearance and body', and 'the experience of the self', there appears to be conflict between culturally imposed assumptions and the personal meanings women make from their experience of breast cancer, implicating the need for stories that reduce the separation of the private and public experiences of cancer (Batt, 1994). Findings point to the experience of breast cancer as one of varying responses, intertwined with dominant representations and cultural assumptions. I hope to have offered the reader an overview of research that has attempted to explore and understand breast cancer from new perspectives. There are two points that stand out for me from this review, which have lead to me to conceptualise my own study. Firstly, much of the above research and literature on breast cancer has been generated within the field of nursing.
Whilst this research is something that I feel I can learn from as a trainee counselling psychologist, I also feel further research focusing on the individual voices of women may continue to add new perspectives. The discipline of counselling psychology values collaboration of research and practice from a multidisciplinary framework (Packard, 2006), therefore, pointing to an opportunity for the field of counselling psychology to share their unique perspectives and values to enhance the field of psycho-oncology. By embracing the aims of feminist research, future studies promoting recognition of social and emotional conflict that may occur for any individual, has the potential to better understand and improve the support offered to women with breast cancer.

The second point stems from Bredin's recognition that, "despite the wealth of literature concerning the impact of breast loss...there have been few studies...directly quoting a woman's private perspective; how in her words she experiences her changed body" (1999: 1113). Loveys and Klaich (1991) concur, suggesting that women's concerns ought to be addressed as women describe them, rather than based on clinical and prescriptive models of research. I was also aware of this, when carrying out a systematic review of the literature on the impact of breast cancer on women's identity in the second year of my doctorate in 2013; very little is said about individual stories in their own right. Much of the literature focuses on themes arising from a data set, rather than focusing on the wholeness of an individual story. Therefore, I feel there is scope to rectify this and bring more voices to life.

2.3 Rationale for a narrative inquiry

As discussed, a feminist approach offers a suitable framework for researching women's experiences and exploring implications of such research for studies of illness (e.g. Seibold, 2000; cited by Thomas-MacLean, 2004). With health psychology and psycho-oncology research having largely been influenced by the medical model, as a counselling psychologist in training, I feel somewhat uncomfortable to rely solely upon this when developing my practice. It is for this reason that I turned to feminist research. I see the switch in attention as representing a change in the purpose of undertaking research (Josselson, 1996; cited by Etherington, 2004), and it is from this change that I will discuss with the reader my rationale behind using a narrative inquiry approach. I draw explicitly on the work of Kasper (1994) to form a foundation for the objective of this current study. Kasper's main objective was to explore "how to begin from our own centre, how to begin from our own experience, how to make ourselves as women the subjects of the...act of knowing" (Smith, 1979: 154: cited by Kasper, 1994: 265). Kasper's methodology is based
on "the belief that the essential meanings of women's lives can be grasped only by listening to the women themselves" (1994: 266).

Taking this foundation into account, I will now discuss a narrative inquiry approach to listening to the women themselves and make the women the subjects of the act of knowing. The study of 'narrative' characterises the phenomena of unique human experience (Connelly & Clandinin, 1990), fitting with my concept of a person is one of active, meaning-making and self-actualising (Cooper & McLeod, 2011), engaged in constructing their lives. Whilst narrative methodology will be discussed in Chapter 3, I offer now a brief history of narrative as a way of characterising the phenomena of human experience. I will then discuss how narratives can be used to make meaning of illness experiences. I hope in this section to highlight to the reader the importance of narrative, not only to the field of oncology, but also aligning with the emancipatory aims of feminist research traditions.

2.3.1 Locating the 'narrative turn'

We as humans tell stories by nature. The stories we tell are less about facts and more about meaning. Consequently, there appears to be "a narrative truth in life that seems quite removed from logic, science, and empirical demonstration" (McAdams, 1993: 28). This different way of understanding, referred to as the 'narrative turn', was located by Kristen Langellier (2001) as beginning in the 1960's, alongside four movements: 1) critiques of positive modes of inquiry in social science, and their realist epistemology; 2) the increase of memoir writings in literature and popular culture; 3) the new identity movements, with efforts to emancipate marginalised groups; and, 4) the growing therapeutic culture, whereby personal life was explored through various therapies. In the 1980's, studies began exploring the diversity of women's experiences, moving away from realist representations of the female subject told from a distant standpoint (Riessman, 2008). Both the narrative turn and feminist approaches made efforts to emancipate women, and turn their focus to the narrator.

Narrative researchers all hold in common the focus of their study; stories, narratives or descriptions of a series of events, and the emergence of the narrative turn has been explained in several historic accounts (Pinnegar & Daynes, 2006). Throughout the 1980's published books by scholars such as Elliot Mishler, Ted Sarbin, Jerome Bruner and Donald Polkinghorne all contributed to the widening narrative path (Riessman, 2008). In his contributions to narrative theory in psychology, Jerome Bruner (1986) argues that human beings understand the world in two different ways of knowing; i) the 'paradigmatic mode'
of thought, in which we seek to comprehend experience in terms of reason and logical proof, from a positivistic paradigm, and ii) 'narrative mode' of thought, concerned with our wants, needs and goals. As explained by McAdams (1993), the 'narrative mode' is the mode of stories, in which we might make sense of events despite the ambiguity we experience as part of our existence as human beings.

Reflecting upon the aim of this study as continuing to explore the meaning of illness from new perspectives, and representing women's lives in their own terms, the 'narrative mode' of thought appears fitting. Charon (2006) notes that narrative understanding enables health care professionals to "understand particular events befalling another individual not as an instance of something that is universally true but as a singular and meaningful situation" (p.9). It is from this stance of acknowledging and establishing 'meaning-making' as a central concept to psychology that I will now move this discussion forward.

2.3.2 The act of making meaning

In his book *Acts of Meaning* (1990) Bruner attempts to illustrate a psychology that concerns itself centrally with meaning, contrasting with traditions psychology born into positivism, whereby the subjectivity of beliefs and desires are avoided in favour of logic, proof and empirical observation (Bruner, 1990). Bruner describes a cognitive revolution whereby the mind was equated to a metaphor of computation, using terms such as 'information' rather than 'meaning', and 'processing of information' as opposed to 'construction of meaning'. Bruner's hope was to replace this objectivist focus of psychology by bringing 'mind' back into the human sciences, for a more "interpretive approach to cognition concerned with 'meaning-making'" (Bruner, 1990: 2).

Bruner (1990) posits that culture should be a central concept for psychology as individuals use shared modes of discourse to negotiate differences of meanings and interpretation. This is fitting with the view of feminist theory that encourages a philosophical, historical and social dimension, moving beyond a purely psychological, individualised view of a person. Bruner suggests that behavioural sciences view of internal processes or mental organisation as being linear and uniform ignores the importance of a meaning-centred, culturally-oriented psychology. This lead psychology towards a deeper objective of understanding the mind as a creator of meaning. I hope at this point to draw the reader's attention to the conceptualisation of this current study, and how Bruner's arguments for grasping the mind in the context of culture are related to my study. As discussed above, psycho-oncology traditionally focused on quantitative measures of well-being. However, this appears to ignore important aspects of the process of self construction. Mair wrote:
"Stories are the womb of personhood. Stories make and break us. Stories sustain us in times of trouble and encourage us towards ends we would not otherwise envision. The more we shrink and harden our ways of telling, the more starved and constipated we become." (1989: 2)

It is interesting to note the use of physical language here of being 'starved' and 'constipated', connecting shrinking away from storytelling with physical struggles. People experiencing cancer are already entwined in a physical struggle, and Mair's words, although metaphorical, imply that to stifle the opportunity to tell a story may heighten this physical struggle. Put simply, there is a relationship between human experience and narrative, with human life being characterised as bearing within it a 'narrative structure' (Crossley, 2000a). Considering this narrative structure in terms of the experience of a life-threatening illness, implies its potential to "throw into relief our routine and taken-for-granted expectations, highlighting the way in which a lived sense of coherence, unity and meaning normally prevail" (ibid: 528). This brings into question the impact this loss of semblance has on a person's sense of meaning and coherent identity. Garfinkel (1984; cited by Crossley, 2000a) posits that our taken-for-granted assumptions about time and our projections into the future only appear visible following a shock or trauma. Consequently, taking a narrative perspective, one could say that a disruption to life caused by chronic or serious illness facilitates the recognition of the narrative configuration of life, by revealing the prior assumptions and life narrative of an individual. More specifically, by hearing illness narratives, our understanding of illness may be enhanced, and the way in which narratives are recuperated and reconfigured will be available to practitioners (Frank, 1995).

The following section will discuss possible ways people make an experience such as breast cancer meaningful in the hope to present to the reader potentially important implications to the field of psycho-oncology.

2.3.3 Making meaning through illness narratives

"Serious illness is a loss of the destination and map that had previously guided the ill person's life: ill people have to learn to think differently. They learn by hearing themselves tell their stories, absorbing others' reactions, and by experiencing their stories being shared" (Frank, 1995: 1).

Victor Frankl (1962), when reflecting on his experience of surviving Auschwitz, concluded that meaning is an essential part of suffering. Consequently, the different meanings that individuals place on their experience of events such as illness may influence the way in
which they deal with that illness or disease, with such experiences being cognitively constructed rather than an objective reality. Through becoming narrators, we can begin to make meaning of our stories. Mathieson and Stam (1995) posit that in the case of cancer patients, stories have a special meaning; as they negotiate their way through changes and disruptions, there is a renewed sense of urgency for making sense of life. Whilst published accounts of breast cancer and thematic analyses of illness experiences are now prevalent within the literature, few have questioned the structure of such stories in relation to the meaning of illness (Thomas-MacLean, 2004). Frank's (1995) exploration of various sub-genres of illness narratives in *The Wounded Storyteller* is a useful way of understanding how stories are created and presented, contrasting to the traditions of categorising stories into themes. Moreover, they offer a means to enhance understanding of the intersection of culture, meaning and experience, hence fitting with a feminist perspective that emphasises the importance of acknowledging the impact of social assumptions on the experience of the individual. In this section, I will explore Frank's work in relation to illness and breast cancer, beginning with a description of the narrative types, and then relating them to stories of breast cancer.

Using the concept 'narrative type', Frank describes three types of illness narratives (1995). A 'narrative type' is described by Frank as "the most general storyline that can be recognised underlying the plot and tensions of particular stories...that cultures make available" (1995: 75). Despite this classification, Frank acknowledges their complexity, and the way in which individual's stories are likely to alternate and repeat different narrative styles. Frank begins with the 'restitution narrative' (1995: 77), a narrative that focuses on a movement from health to sickness, looking to return to health in the future. This is a narrative that Frank observed as one most commonly used in the stories told by ill people, and can be viewed as helpful, reflecting a natural desire to get well and stay well. However, he warns that it may also be thought of as a medicalised story, one that "people learn...from institutional stories" (Frank, 1995: 78). Thomas-MacLean (2004) notes that these institutional stories reflect Western medicine's emphasis upon diagnosis, treatment and cure, and may lack some of the subtle nuances of the meaning of illness.

The second narrative type that Frank discusses is referred to as the 'chaos narrative', a storyline which "imagines life never getting better" (1995: 97), revealing the breakdown of orderliness of illness narratives (Williams, 1984: cited by Thomas-MacLean, 2004). Whilst hearing these narratives is difficult and potentially anxiety provoking, Frank (1995) emphasises their importance for uncovering and enhancing understandings of illness.
experiences. In a sense, this narrative style contradicts the restitution narrative, by highlighting the pretence of control sought by medicine (Frank, 1995: 100).

Finally, the 'quest narrative' shows how illness may be considered useful (Frank, 1995). Frank regards the quest narrative as being equally familiar to our culture as restitution narratives in that most published accounts of illness follow the format of illness as a challenge offering the potential for change. It can perhaps be linked with previous discussions of transformations and post-traumatic growth (see Joseph, 2011). Frank reflects that "as the ill person gradually realises a sense of purpose, the idea that illness has been a journey emerges” (1995: 117). A particularly strong quest story is told by Audre Lorde (1980), in which she writes of claiming her own body back from the social pressures to wear a prosthesis. Rather than conceal her difference, she chooses to affirm it. Whilst quest narratives may be considered therapeutic for their potentially positive transformative nature, Frank (1995) notes an inherent danger of showing movement through illness as too clean, devaluing those who do not experience such a transformation. This reflection is similar to the discussions above, whereby feminist research notes the complexity of the experience of breast cancer; it is not a clean journey from illness to transformation. In particular, Arman and Rehnsfeldt (2003) note the tendency for researchers to pass over the darker sides of suffering to the change process, something which may be perpetuated by the quest narrative. Moreover, Thomas-MacLean (2004) suggests that these clean narratives are the basis for cultural and social prescriptions for living with illness, creating an assumption that following illness, people grow and transform, leaving little room for alternative meanings.

Relating these three narrative types to breast cancer stories, Thomas-MacLean (2004) applied Frank's work to a study of embodiment after breast cancer. Restitution was found to be the narrative type favoured by most women, suggesting a desire to return to 'normality'. However, due to the altered nature of their bodies as a result of treatment, Thomas-MacLean (2004) suggests potential difficulties with sustaining a restitution narrative, and offers instead a narrative of reconstruction. Thomas-MacLean reflects on the prolific nature of the restitution narrative in the stories of her participants, noting that whilst the women do not deny the experience of illness, restitution perhaps is a way of providing order in the midst of chaos (Thomas-MacLean, 2004). In contrast to the restitution narrative is the story of chaos; one that Thomas-MacLean found to feature most prominently in situations, such as discussions of bodily difficulties. Importantly, participants noted the importance of hearing about disruption, and acknowledging chaos,
something that Thomas-MacLean regards as having the potential healing nature of chaos stories.

Quest narratives were not particularly prevalent in the stories told by the women in Thomas-MacLean's (2004) study. Whilst some women did discuss changes that had occurred, the link of these changes with a quest type narrative was somewhat tenuous and uncertain. Thomas-MacLean, therefore, questions how useful published accounts of breast cancer that follow the format of a quest narrative really are. Some women critiqued such public narratives, acknowledging the fact that elements of chaos would result in clearer and more comprehensive stories of breast cancer. Thomas-MacLean concludes that Frank's work provides a means of engaging with stories and putting into words the complex and multilayered experience of breast cancer.

Overall, Frank's (1995) conceptualisation of narrative types has lead me to consider my own study in terms of genres of illness narratives, rather than in terms of thematic approaches that are predominant in most studies of the experience of breast cancer. Bury (2001) also offers alternative illness narratives, which offer additional insights into the subjective patient view, and are a means by which links between body, self and society are articulated. Moreover, he argues that attention to narratives has the ability to provide clues to ways in which body, self and society are linked in late modern culture. Bury therefore suggests a framework for analysing illness narratives, discussing three forms that need to be considered: contingent narratives; moral narratives; and core narratives. He regards contingent narratives as describing events, their proximate causes, and their everyday life. Contingent narratives are divided into two broad types: a categorical view of illness, sharing characteristics of a biomedical approach; and a spectral view, taking a more social or personal perspective.

The second type of narrative form within Bury's framework is a moral narrative, whereby sufferers seek to account for changes between themselves, their illness and their social identity. Finally, core narratives reveal connections between the lay person's experiences and deeper cultural levels of meaning attached to suffering and illness. In relation to this, Kelly (1994) identifies a series of genres underpinning all forms of narratives. These include heroic, tragic, ironic and comic, and regressive/progressive narratives. Given the complex character of illness narratives, Bury (2001) reflects that narrative analysis of illness in health related settings need to be treated with caution. This can be summarised in his concluding remarks that "a particular self is constituted through these narratives,
occasioned by the presence of a listener, her questions and comments” (Bury, 2001: 282-283).

In the above sections, I have discussed the appropriateness of a narrative approach to research as a way of challenging generalisations and assumptions based on social stereotypes, with narratives being regarded as a valuable source of experiential knowledge (e.g. Frank, 1995; Polkinghorne, 1988; Sandelowski, 1991). Stories may then enhance understanding of illness and may also facilitate positive therapeutic relationships between health care professionals and women with breast cancer. Taking Frank's (1995) approach to understanding illness narrative as a particular example, I hope to have offered to the reader a possible framework from which to engage with stories, situating them in social contexts. I offer Bury's framework to expand the discussion of illness narratives and to also reflect upon analysis of illness narratives as interpretive acts of trying to understand the "inevitable gap between the experience...and any communication about it" (Riessman, 1993:10). For me, Frank's approach proved the most appropriate for a number of reasons. His classification of restitution, chaos and quest narratives were useful when working as a trainee counselling psychologist at The Christie, offering me a way of understanding different experiences of illness. Consequently, I felt drawn to engage with his framework of 'narrative types' again during the research process. There is a sentence that Frank writes that perhaps conveys best the underlying reason for my use of his framework in my research: "The ill person who turns illness into story transforms fate into experience" (pixy). I feel Frank's statement fits with the intentions of my research – turning illness experience into meaning, and helping people to tell a story that fits their experience.

2.4 Conclusion

This chapter aims to conceptualise the basis for my research in the context of feminist and narrative theoretical frameworks, first offering an overview of the psychology of illness, and the literature of psycho-oncology. With traditional methods of research in psycho-oncology tending to conform to the medical model of classifying patients according to emotional reactions, (Mathieson & Stam, 1995), personal perspectives are not heard. With the values of counselling psychology, emphasising diversity, and valuing social justice and advocacy (Packard, 2009), I posit that research linking the fields of counselling psychology and psycho-oncology may offer new perspectives on the stories of women with breast cancer.

The goal of feminist research has been "to address women's lives and experience in their own terms, to create theory grounded in actual experiences and language of women" (Du
Bois, 1983: 108: cited by Kitzinger & Wilkinson, 1997), challenging assumptions from large-scale, quantitative research. It acknowledges that experience takes place in an ever-changing social environment, one in which views of breast cancer have changed dramatically over recent decades (Kaiser, 2008). The impact of these changes on the experience of breast cancer, and the meaning-making process of women is an area for potential future research. For instance, on a social level contemporary constructions of breast cancer presents a certain image of the survivor not fitting with the experience of all women (see Kaiser, 2008). This narrative of survivorship supports the medical model wherein illness is diagnosed, treated and cured (Batt, 1994; Frank, 1995). On an individual level, women have opportunities to join the dominant culture via consumerism (Kaiser, 2008), but beyond that culture, few alternatives exist. This poses the question; why does this current image of the survivor persist if it does not work for many women? In fact, although qualitative studies of the experience of breast cancer are now prolific, little detail is provided of whole stories or interpretations of individual stories in their own right.

In an attempt to offer an appreciation of the wholeness of individual stories, I suggest an approach to research from a 'narrative mode' of thought, fitting with the humanistic stance of counselling psychology. The intention of such research would be to further stimulate discussion, rather than attempt to make universal claims. The hope of this present study is that such discussions may improve practitioner's ability to collaboratively explore with female cancer patients the meanings they make of a diagnosis. Moreover, it appears fitting to allow whole stories to be heard in the context of research that highlights the feelings of being isolated, silenced, and unable to express suffering experienced by people with cancer (Rydhal-Hansen, 2005; Rasmussen et al, 2010).

In the following chapter, I will build on the foundations of Chapter 2 and describe the methodological details of the narrative approach I have chosen in this study. A detailed account of the research design used is described along with the participant selection process and the data collection method. The restorying process and method used to interpret the stories individually and as a whole will also be discussed.
Chapter 3

Research Methodology and Generation of Narratives

### Organisation of Chapter 3

**Introduction**  
Introducing qualitative research  
Using a narrative research approach  
Narrative analysis – an overview  
Working with stories  
Conclusion

3.1 Introduction

This chapter presents the design and conduct of my research. Chosen in relation to the conceptualisation in the previous chapter, the methodology is intended to invite voices of the storyteller to be heard. The specific task of the methodology is to reflect upon possible insights and interpretations drawn from the narrations. The study used a qualitative framework, specifically drawing on a narrative perspective in conjunction with the feminist intent to reverse the unequal status of the researcher imposing a set of questions upon the participant in order to meet the goals of the research. This decision is based on the research findings discussed in Chapter 2, highlighting the incongruity between many dominant social assumptions surrounding breast cancer, and the actual lived experience of women with breast cancer. A narrative researcher begins from a curious, unknowing position (Anderson & Gehart, 2007), and it is my intention to embed this stance throughout the methodological approach to this study.

At times narrative research has been criticised for being more like art than research (Lieblich et al, 1998), implying that it lacks scientific rigour. One could argue that attempting to achieve rigour would contradict the underlying assumptions of narrative research; how could a scientific model still capture the unique way in which people imaginatively engage in the process of making sense of a story? However, research rests on the assumption that it is the responsibility of the researcher to provide "*a systematic and coherent rationale for their choice of methods*" (Lieblich et al, 1998:2). This is the intention of this chapter.
3.2 Introducing qualitative research

3.2.1 Positioning qualitative research

Qualitative research is based on a paradigm that places the subjectivity of researcher and participant at the centre of the research (Ponterotto, 2005; Elliott et al, 1999). Whilst quantitative research objectifies individuals without context, "qualitative researchers study things in their natural setting, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them" (Denzin & Lincoln, 1994: 2).

There are many forms of qualitative research, all shaped by epistemological origins. Consequently, it is important to note that the epistemological standpoint influencing my research comes from associations with concepts of constructivism (or interpretivism). Qualitative research and the seeds of constructivism-interpretivism can be traced back and associated with the set of beliefs posited by Immanuel Kant (1881/1966) in his Critique of Pure Reason. Snape & Spencer (2003) summarised these beliefs as follows:

- perception relates not only to the senses but to human interpretations of what our senses tell us
- our knowledge of the world is based on 'understanding' which arises from thinking about what happens to us, not just simply from having had particular experiences
- knowing and knowledge transcend basic empirical enquiry
- distinctions exist between 'scientific reason' (based strictly on causal determinism) and 'practical reason' (based on moral freedom and decision-making which involve less certainty). (Snape & Spencer, 2003, p.6-7)

Kant's work highlights a central tenet of constructivist thinking: that reality is constructed by the research participant. Along this line of thinking, we can gain insight into how meaning is constructed by listening to stories told by women with breast cancer.

My philosophy, as a counselling psychologist, is one that embraces a set of humanistic values and ethics, whereby my focus is individual subjectivity, in keeping with cooperation, collaboration, and co-creation within a therapeutic or research relationship. Consequently, when searching for a research paradigm fitting with humanistic values, my hope was to involve the women, not just in the interview, but thereafter, throughout the restorying process, should they wish. Moreover, as I encountered each research participant, my intention was always to maintain openness to multiple meanings and truths, all of which are based on what our senses tell us (Snape & Spencer, 2003), and are
dependent upon the context in which the encounter takes place. This will be discussed in more depth in Chapter 6, ‘Reflexive Analysis’.

### 3.2.2 Qualitative research in psychology

Moving away from the dominant positivist and postpositivist research paradigms associated with quantitative methods (Ponterotto, 2005), Gergen (2001) asserted that by broadening the perspectives and research methodologies within psychology, the profession will grow in knowledge and its ability to impact society. Within counselling psychology, there has been recognition that qualitative methods are more congruent to the practice and philosophy (Morrow, 2005). However, by changing the methodological approach, the question of 'criteria' for qualitative research is posed; many assumptions underpinning quantitative research are inappropriate for qualitative research. Therefore, when judging such research we should do so with flexibility and reflexivity throughout the research process (Parker, 2004). This will be discussed more in the sections below.

Throughout the thesis, I hope to make transparent my own position as a counselling psychologist, and the context in which I have carried out this research. For instance, when justifying the study in Chapter 1, my own interests were made explicit to the reader. Moreover, in Chapter 6 I will build on this by reflecting upon the way in which the philosophical stance of my training impacts my approach to research. This approach moves away from the traditional neutrality of a quantitative researcher, by drawing attention to the journey the researcher has taken towards the research. Consequently, the concepts of validity and reliability are replaced by a preference to explore different ways of interpreting. Mischler (1990) suggests that focusing on the trustworthiness of a study rather than its ‘absolute truth’. By retaining a reflexive stance throughout the thesis, I hope to provide the reader with information that locates the perspectives that are offered. The criteria of trustworthiness and credibility applied in this study will be discussed below.

#### 3.2.2.1 Transparency

By ensuring that the reader is aware of each stage of the research process, the hope is that a better understanding is gained of the interpretations and analysis of the data. In this chapter, the reader is able to follow the methodological process. In the following chapter, the stories themselves are presented as a whole, for the reader to see for themselves. In Chapter 5, I offer my own interpretation of the stories that the reader has seen for themselves. With an awareness of the possibility of multiple interpretations, in Chapter 5 I present direct quotes from the stories as a way of showing to the reader links between the
narrations and my interpretations. Finally, in Chapter 6, I offer to the reader insight into my own self reflection, making transparent my theoretical and philosophical standpoint.

3.2.2.2 Coherence

The process of coherence involves the researcher attempting to put different parts of the story together to maintain a whole, complete and meaningful image. Recognising the study’s interest in grasping the meanings of these women’s lives by listening to the women themselves (see Kasper, 1994), this was a particularly important aspect of the research. Within this chapter I will explain the way in which I changed the original transcripts to prose. Following this, in Chapter 4, the stories will be presented as a whole. Finally, in Chapter 5, the analysis chapter, direct quotes from the stories will be presented to strengthen the coherence of the interpretations made, and keeping the original and whole stories alive throughout.

3.2.2.3 Persuasiveness

Riessman (1993) posits that persuasiveness is an important aspect of trustworthiness and validity. According to Lieblich et al (1998), persuasiveness refers to the possibility that a number of researchers will evaluate the data. Whilst in this study I was the only one to interpret the stories, I also discussed the interpretations I made at depth in supervision, with both my supervisors and also my peers in group supervision.

3.2.2.4 Pragmatic Use

Whilst making universal and generalisable claims is not the intention of qualitative research, Riessman (2008) claims that the pragmatic use of narrative research leads to research responsibility to contribute to future research and to social change. She advises of the following criteria:

- Describe how the interpretations were produced
- Make the process visible
- Make the primary data available

Following these criteria, in Chapter 1, I clarified the genesis of the study, stating my study aims and the potential impact. In addition, in Chapter 7, I discussed the potential contribution to knowledge in the field of counselling psychology in relation to working therapeutically with women with breast cancer. I hope that this research will be relevant to fellow counselling psychologists with an interest in psycho-oncology.
3.3 Using A Narrative Research Approach

"People shape their daily lives by stories of who they and others are and as they interpret their past in terms of these stories. Story, in the current idiom, is a portal through which a person enters the world and by which their experience of the world is interpreted and made personally meaningful." (Connelly & Clandinin, 2006: 375).

3.3.1 Choosing a method

With a focus on the 'meaning-making' processes that take place following breast cancer, I was drawn to a narrative methodology. Narrative inquiry focuses on the subjective experiences and stories of individuals (Parker, 2005), providing an understanding of how human beings make sense of their world (Jovchelovitch & Bauer, 2000), and develop their identity in relation to experience.

Polkinghorne (1988) argues the main purpose of narrative research as the production of narrative accounts of how individuals understand meaningful events in their lives. I would posit that my research is situated broadly within the narrative inquiry field of narrative research, "the study of experience understood narratively" (Clandinin & Huber, 2010: 1). Therefore, the motivation behind choosing a narrative inquiry methodology was to develop insight into how women with breast cancer understand the experience through narrative. Crossley (1997) posits that constructing meaning around one's experience of ill health has psychological benefits. By thinking narratively about such phenomena, there is an opportunity to challenge the dominant story, and allow for an investigation of the experience of cancer from the patient's point of view.

Three commonplaces of narrative inquiry, temporality, sociality, and place (Clandinin & Huber, 2010), serve as dimensions that seemed appropriate to my study. The importance of such dimensions will become evident in the sections below as I discuss the storygathering process and the relevant aspects related to the telling of the stories. However, in summary, it is the recognition of how stories unfold in the "multidimensional, ever changing life space"(Connelly & Clandinin, 2006: 481). Both the stories told and the interpretations and analysis will shift depending upon the time and place in which they were told, and the identity of the person listening and interpreting these stories. My own identity will be discussed in more depth in the reflexive analysis in Chapter 6. Moreover,
when I present the stories to the reader in the subsequent chapter, I present situation (in other words, the place and time) in which the stories were told.

Some narrative researchers have questioned how research can be productive if the narratives being studied are inherently unstable (Fay, 2004), and changing. This can perhaps be answered by acknowledging all narratives in terms of the dimensions of time, social conditions, and the context, and the relational aspects of knowledge and meaning (Gergen, 2001). I hope to embrace this inherent subjectivity through my choice of methodology and my reflexive stance throughout.

3.3.2 Planning the interview

When considering the interviews with each participant, my prior therapeutic work with cancer patients and their families was brought to mind. I was reminded that needing a space to reflect and contemplate the changing of one's sense of self (Clarke et al, 2010) was often what my clients desire. Moreover, central to the methodology of this study is the belief that to grasp the meanings women make from their experience of breast cancer, we must listen to the women themselves. Therefore, by freeing the research of constraints such as interview scheduling, I hoped that the women I met would be liberated to explore their narratives in their own words.

My broad aim for each encounter was to create a space where my participants felt willing to share personal stories with a stranger. Therefore, my starting point was to ensure confidentiality throughout the process and then to remain actively engaged when listening. The informal interview technique of inviting rather than questioning had the intention of encouraging each storyteller to speak about issues pertinent to them as individuals. I questioned the type of relationship that would be developed, and how we would interact together in such an unusual scenario. Fine (1994) for example, conceived the interaction of a narrative interview as a partnership, focused on empowering the storyteller. Kvale (1996) refers to this collaborative relationship using the metaphor of the researcher as a 'traveller', journeying to distant places and bringing back stories about other people's lives. Using another metaphor, Josselson (2013) refers to the interview as a 'dance', with the researcher setting out to follow the motion of the interviewee. I found that reflecting upon these metaphors helped me to consolidate and clarify what I hoped to do throughout each narrative encounter.

A fundamental assumption of this study is that every woman I interviewed is "an expert on her life, its meanings, and her beliefs" (Kasper, 1994: 268), and, therefore, I hoped to
enable the women to speak on their own terms. Whilst I did of course engage in conversation during the interview, my questioning only clarified or expanded a topic or a theme that had already been addressed by the participant of her own accord (ibid). As I contemplated the interviews prior to meeting each participant, I expected initially to hear what Labov and Waletzky (1967) called ‘orientation’, meaning a short summary of their experiences. They then went on to posit that embedded in every narrative is the ‘evaluation’, referring to the markers of what a particular experience means to the person. My task therefore was to move over the course of the interview, from the surface level of the initial orientation, to the deeper level of an individual’s meaning, by entering the world of the participant.

3.3.3 The Storygathering Process

3.3.3.1 Timeframe

I conducted the interviews in the private sector of an NHS hospital specialising in cancer care. The interviews ran over a time period ranging from May 2013 to September 2013.

3.3.3.2 Selection Process

I encountered each woman in this research via their oncology consultant at the private cancer hospital, and therefore I relied on him for the initial selection. When I met him to discuss my research, he informed me that he had women in mind who discussed their cancer openly, and whose emotional well-being was, in his opinion, sound. The consultant and I agreed that he would discuss my research with these patients and if they were interested, the nurses would provide them with my consent and information sheets for them to read through (see Appendix A & B). As far as my knowledge, there were no women who were approached who subsequently declined. Each woman had a minimum of two weeks between signing the consent sheet and meeting with me, allowing them time to opt out if they wished. It was always made explicit to the women that this was voluntary, and played no part in their cancer treatment. The right to end the interview was also emphasised by me from the onset of our encounter.

When participation was agreed, interviews were organised via the clinic manager, who emailed me with suitable times and dates for each of the women. When the time came for me to meet each woman, I was brought to their private room by either the clinic manager, or one of the nurses. These rooms were all enclosed, meaning that the stories they told were not being overheard. It is perhaps important to note at this point that these women had a relationship with both the nurses and the clinic manager, which potentially might
have influenced their willingness to share their story with me. As will be highlighted in Chapter 4, I had not met the women prior to the interview, with one exception; I met Judy very briefly prior to our interview, when I was in the clinic for another interview, the clinic manager introduced me to Judy. At this time, she informed me that she had a long story to tell. I hope this section outlines clearly to the reader, the path I took to meeting these four women. The women I met through this consultant were all at very different stage of their breast cancer journey, with three in fact receiving treatment for secondary cancers. Therefore, as will be seen through the stories, this research became not just about breast cancer, but also about living with a chronic illness in the current social context.

3.3.3.3 Inception of the Relationship

As discussed above, the four elected participants were initially contacted by their oncology consultant, who made them aware of my research. Therefore, my association with all of the participants was through their consultant, having not met any of them on a previous occasion prior to them taking part in the research. Although each participant may have had preconceived ideas about me, the inception of the relationship meant that I was starting with a relatively blank slate, and it was my responsibility, within a short space of time, to be perceived in a professional yet welcome manner. I focused on what Josselson (2007) refers to as an ethical attitude towards my participants, "a stance that involves thinking through these matters and deciding how best to honour and protect those who participate in one's studies while maintaining standards of responsible scholarship" (p.538). In an effort to avoid exploitation, and earn trust, I did not ask direct questions about potentially sensitive topics, only posing further questioning around such topics if a woman had raised them herself.

My hope as a researcher was to facilitate a meaningful process of storytelling for each woman involved in the research. However, when dealing with human lives, we can never be sure at the onset what effect we as researchers will have. This will always remain a dilemma, and it was one that I thought of often when asking women to tell their story in relation to such an emotive event in their life. By maintaining an ethical attitude, I hoped that I could then remain responsive throughout my encounter with each storyteller to the complexities occurring when dealing with real lives of real people.

3.3.3.4 Immediacy versus Preparedness

As mentioned, the women were given information and consent sheets at least two weeks prior to meeting with me. Therefore, they knew the basics of my research and may well
have thought about what stories they were going to tell me. However, they were not given information of the form of the inquiry, and to this extent I hoped for spontaneous responses to my elicitation of storytelling and unstructured questioning. I hoped this immediacy would allow me, as the researcher, to subtly integrate myself in the midst of each woman's ongoing experiences (Clandinin & Huber, 2010).

3.3.3.5 Place

The location in which interviews are conducted can exercise considerable influence on what participants say, and this is of relevance to this research in that the interviews took place in a hospital room of The Christie Clinic whilst the women were present for cancer treatment. Connelly and Clandinin (2006) recognise that "all events take place someplace" (p.481). Whatever place that may be, one could argue that our identities are linked with our experiences in this particular place (Clandinin & Huber, 2010). In relation to this study, the women I met were telling me their story in a room in a hospital whilst having chemotherapy. The memories linked to their experience of this particular setting, and the meanings they make of these experiences are likely to be different to if I had met them in their homes for example. Taking this into account, in the subsequent chapter whereby I present the stories, I will precede the stories with a brief description of the individual contexts in which the stories were told to me.

3.3.3.6 Mediation and Sociality

I chose to take a low mediation methodology using an unstructured, low mediation approach to the interviews. One could perhaps assume that there would be no direction, but this was by no means the case, as each encounter was bound by my research question (Josselson, 2013). Despite avoiding an explicitly structured interview schedule, I used the idea of the 'Big Q Question' and the 'Little q Question' (Josselson, 2013), which loosely mediated the direction the interview took. To this end, it was not structured with a question and answer format often associated with interviews, but was bound to an extent by my research question, as this was the purpose of the interview. For the purpose of this study, the Big Q Question was 'meaning-making and breast cancer', and the Little q Question was 'How do women make meaning of breast cancer?' These questions combined were intended to gain insight into the meaning-making process following an experience of breast cancer.

A particular area of concern for me relating to using a low mediation approach was in regard to the relationship between me and the storyteller. The fact that we did not have a
prior relationship implied a potential difficulty and anxiety for each storyteller to enter storytelling mode with a stranger. I therefore began each encounter by following a set of steps to ensure participants were aware of important points with regards to the research, and knew what they were entering into. These steps are described below.

i) **Formal Consent**

Although I had gained formal consent in the form of university required documentation, I was aware of the detrimental effect that such formalities may have on the relationship I hoped to build. Therefore, I began each interview by softening the consent process by reintroducing it verbally (Josselson, 2013). The following extract offers an example of such an introduction.

**Extract 3.1**

<table>
<thead>
<tr>
<th>Introducing informed consent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Interviewing Caroline</strong></td>
</tr>
<tr>
<td>Before we start, I just need to introduce a formality. I know you have already signed the informed consent sheets you were given before we met today, but I wanted to mention it again today before we start. So, everything you tell me today will be completely confidential, and what I write will disguise your identity so that no one will be able to identify you. And most importantly, let me know if at any time you wish to stop talking and I will turn off the recorder.</td>
</tr>
</tbody>
</table>

ii) **Orienting the Participant to the Question**

Following the introduction to informed consent, I then reminded the participant of how we have come together, by orienting them to the 'Big Q question' and 'Little q question', as can be seen from the following excerpt.

**Extract 3.2**

<table>
<thead>
<tr>
<th>Introducing the question</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Interviewing Rosemary</strong></td>
</tr>
<tr>
<td>As you may have read on the information sheet you were given a few weeks ago, I am studying how women make meaning from breast cancer treatment. So, I am interested in hearing your story and your personal experiences.</td>
</tr>
</tbody>
</table>

The above highlights the fact that I oriented the participant to my general area of interest, but at the same time kept my mediation low, allowing each storyteller to explore their
understanding from their own point of view. Again, the metaphor of the narrative interview as a dance captures this process of co-construction that I hoped to achieve.

3.3.3.7 Ethical considerations

When using qualitative research, research can be judged as ethical in terms of a framework for a certain kind of research ethics in which subjective experience is acknowledged and harnessed (Clark, 1997). Discussed below are the formal aspects of research ethics. However, beyond this my intention was to maintain an ethical stance acting as an umbrella for the whole research process.

Initial ethical clearance was carried out through the School of Education, University of Manchester, and was assessed as being high risk due to the potential vulnerability of the participants following a discussion about sensitive issues surrounding cancer and cancer treatment. Therefore, the study had to be cleared through the University Research Ethics Committee (UREC). I placed emphasis throughout the whole ethical clearance process on my being trainee counselling psychologist and having worked therapeutically with cancer patients at The Christie Clinic on a one year placement. Consequently, I felt able to engage in conversations of a sensitive nature, and would therefore offer a contained environment for the women to tell their story. However, when I carried out my research, my placement at The Christie had ended, and therefore there was no risk of me having a dual role of therapist and researcher.

Along with the ethical clearance from the University of Manchester, the research also had to be approved by Sarah Cannon Research UK. After a short teleconference and a review of the documentation, it was confirmed that the Research Review Committee (RRC) had no objections for the study proceeding at The Christie Clinic (See Appendix D for RRC letter). To address the ethical implications of this study, I followed the British Psychological Society ethical principles for conducting research with human participants (2010). Consequently, informed consent was required from the participants (See Appendix B). In addition, participants were also informed that they could withdraw from the study at any stage, and that no reference would be given to their personal identity. To achieve confidentiality, all files were protected with passwords.
3.3.4 The Process from Speech to Prose

3.3.4.1 Transcription Process

The main products from the narrative encounters were the tape recordings of the four interviews, lasting from one hour to ninety minutes. These were transcribed, indicating the following:

- pauses, although I did not indicate duration
- features such as hesitations, erms, laughter
- overlaps in speech

The transcription process was based on the content of the narrative rather than the structure. The participants were informed beforehand that the transcripts would not be published without their consent and therefore they are not included in the Appendices. Only the final restored versions will be presented within the thesis.

The participants were provided with a private copy of the transcripts of their interview. From this they were invited to make further comments or amend their narratives should they wish. Of the four participants I met, nobody amended any part of their original story. The finalised transcripts were then formed, which again, are not available for publication.

Figure 3.1 below summarises the transcription process.

**Figure 3.1**

*Source: Adapted with permission from R.Fay (2004).*
Restorying Process

The final transcripts were then transformed into prose narratives ("restorying"), intended to form part of the final thesis. The participants were aware of this process from the onset, and were informed of further opportunities to amend the restoried versions of their narratives.

As a broad guide to the process of restorying, I followed the procedure outlined by Fay (2004) as a way of converting the transcripts into prose. The first initial editing stage involved forming the transcript into a reader-friendly prose, which involved cutting out the following:

- non-content features of the oral narrative (e.g. "erm", "you know", "kind of")
- repetition of content, false starts, fractured sentences
- indications of pauses and laughter
- my own comments throughout the interaction

Punctuation was then added and text was organised to create sentences and paragraphs, forming the first restorying draft.

Secondary editing was carried out on this draft, which involved some textual reorganisation in order to bring together sections dealing with related matters. This new version once again required further reorganisation into fluent sentences, paragraphs and sections. Section headings were also added. Following completion of the restoried draft, each participant was sent the restoried version of their narrative, giving them a second opportunity to amend. However, none of the women asked for any amendments.

Finally, the text was anonymised where necessary. This produced the final restorying prose of the original transcribed narrative. Virtually all the words used in the restoried prose are those of the participants. Similarly, the flow of the original narrative was maintained and no significant content was omitted, unless requested by the participant. Alongside each restorying version, I offered an introduction to the narrative, recounting my experience and reaction to meeting each participant. My own perspective however will be further elaborated on in Chapter 6.
The process of restorying described above is summarised in Figure 3.2 below.

**Figure 3.2:**

*Source: Adapted with permission from R.Fay (2004)*

The above restorying process can be seen in the following versions of Caroline's narrative: extract 3.3 shows an extract of the original transcript, with extract 3.4 and 3.5 showing the two stages of restorying.

**Extract 3.3**

<table>
<thead>
<tr>
<th>Extract from the Transcription of Caroline's Narrative</th>
</tr>
</thead>
</table>
| C: ...
| ..mer...and the same with my hair...err my hair was, I
| used to go to the hairdressers every six weeks and spend a hundred pounds a time having colour done, and it, hair
| had to be perfect and now I haven’t got any...
| EC:...mhm... |
| C: ...at the moment, I haven’t bothered with a wig, in fact this is the first time I've had a scarf on....
| EC: Ok, so first...time today?
| C: Yeah, I don't, I've just not bothered, I'm not bothered at all, so I think, I....I've been trying to analyse myself a little bit, whether or not..I've not accepted my condition...
| EC:...mhm
| C:...whether I've just compartmentalised it and just kind of, pretended it's a bit of an irritation, or whether actually I'm coping very well, and I'm not sure.
| EC: So, you're kind of torn between two things...
| CW: .....yeah...
| EC: .....and you're unsure....
| C: .....yeah I am unsure and I'm more concerned about erm...my job at the moment and whether, whether my job will be there when I go back...
Extract 3.4

Extract from the Restorying Draft of Caroline's Narrative

It's the same as my hair, I'm not bothered at all, I used to go to the hairdressers every six weeks and spend a hundred pounds a time having colour done. My hair had to be perfect and now I haven't got any. I haven't bothered with a wig, in fact this is the first time I've had a scarf on.

(3)I've been trying to analyse myself a little bit. Whether or not I've accepted my condition, whether I've just compartmentalised it and pretended it's a bit of an irritation, or whether actually I'm coping very well, I'm not sure. I'm unsure and I'm more concerned about my job at the moment and whether it will be there when I go back, as opposed to whether I've actually beaten the disease.

Extract 3.5

Extract from the Final Restorying Draft of Caroline's Narrative

My hair had to be perfect and now I haven't got any. I haven't bothered with a wig, in fact this is the first time I've had a scarf on. From a femininity point of view, I've actually been very accepting of what's happened, to the point where I've actually put weight on. That's unheard of, you don't really put weight on with chemotherapy or when you've got cancer.

Extended examples of the restorying process are offered in Appendix C. The finished narratives are presented and interpreted in the following chapter. The method of analysis is discussed below.

3.4 Narrative analysis – an overview

Narrative analysis refers to "a family of methods for interpreting texts that have in common a storied form" (Riessman, 2008: 11), employing a range of methods to interpret stories and individuals’ construction of meaning (Riessman, 2008). Narrative researchers may focus their attention on the content (what is being told), the structure (how it is being told), or the context (why it is being told) (Squire et al, 2008). Moreover, some researchers may attend to the whole life story (e.g. Mischler, 1999), whilst others focus on sections of the story (e.g. Bailey, 2001).

My own interest lies in how each speaker uses stories to communicate meaning. Throughout the analysis in Chapter 5, my intention is to retain the individual stories in
their own right, focusing on accounts that are preserved, rather than fragmented into categories and distilled into coding units. As argued by Polkinghorne (1988), the main purpose of narrative research is to produce a document that describes an individual's narratives, "the research does not construct a new narrative; it merely reports already existing ones" (1988; 161-162). Moreover, it is important to acknowledge the fact that each woman's ability to interpret the experiences of her life is far better than mine. As argued by Kasper, "researchers who trust the authenticity of the narrator's account recover a wealth of material unavailable to those who are sceptical of, or distrust, what they are told" (1994: 274). Narrative research therefore can allow new and previously unanticipated information to emerge from participants free of our assumptions and prejudices (Gottlieb & Lasser, 2001). Smythe and Murray (2000) however, warn that "some individuals might not respond well to the exigencies of narrative inquiry – that is, to the consequences of being open and reflective about their experience...as narrative researchers we must be prepared to exclude individuals who we believe might have considerable difficulty dealing with these issues" (p.329). Such recommendations to protect participants from harm, however, have the unintentional effect of privileging certain voices (or accounts) over those of others. Whilst narrative researchers aspire to the goal of including all voices in their work, if we take into account difficult ethical issues illustrated by Smythe and Murray, then such goals might prove difficult. In the case of this research for example, as discussed above, the consultant chose patients that he deemed able to cope with an interview that would require them to be open and reflective about their experience. Hence, the stories of these women became privileged over those of women who may be in greater distress. I feel it important to note these difficult ethical issues to make the reader aware that whilst the intention of this research is to hear the individual accounts of women, certain accounts may inevitably be excluded.

In Chapter 5, I will analyse the restoried versions of the original transcript. The restoried versions of my original encounter with each storyteller are undoubtedly interpretive, carrying implications for how a reader will understand the narrative, and also is entirely lacking in evidence of the process of co-construction between me and the storyteller. My decision to present and analyse the restoried prose, rather than the original transcripts is based on my intention to present the experience of each woman, and to study precisely how women might story themselves and their situations, following a breast cancer diagnosis. My intention was not to present a conversational exchange between two women, and therefore I have not included my participation. Moreover, with my interest focusing on "the told' – the events and cognitions to which language refers (the content of
the speech)" (Riessman, 2008: 58), the transformed prose version is an appropriate source for analysis. With narrative analysis being grounded in closely studying the particular, presenting an exact set of rules to analysis is not the intention. Therefore, below I will discuss the way in which I attend to the subtleties of each story.

### 3.5 Working with stories

Riessman (2008) introduced four approaches to analysing narrative data: thematic, structural, visual and dialogic approaches. Moreover, she perceives thematic and structural approaches as the foundation of narrative analysis (Riessman, 2008). All narrative analysis is concerned with content of a story, but in thematic narrative analysis, content is the sole focus (Riessman, 2008); I chose to take such a focus as I hoped to attend to the narrator's experience rather than the narrative itself. Therefore, in the analyses in Chapter 5, my primary attention is on what is said, rather than how it is said, with the aim to develop a theoretical framework, from which to engage with the research questions introduced in Chapter 1.

As discussed above, I will interpret each story individually, with established theory guiding the inquiry process. Based on the emancipatory aims of this research, and the hope to place the women’s experiences at the centre of the research, I felt that thematic narrative analysis would be the most appropriate approach. This is due to the content of the story being kept as a whole narrative unit and regarded as the main resource during interpretation (Riessman, 2008). Riessman acknowledges the personal impact of the researcher on the analysis, and it is for this reason, among others, that I devote Chapter 6 to a reflexive analysis of my own interpretive processes.

I consider the first stage to be accomplished by the story-tellers themselves (Kasper, 1994), in the sense that the choice of material brought to a story is itself a part of the interpretation each woman applies as to her experiences. The subsequent stages will be performed by me as the researcher. I will carry out a number of progressive steps of analysis, aimed at offering an interpretation of the stories by searching for connections between facts and meanings presented in an individual's account. These meanings will then be related to over-arching themes in each woman's breast cancer crisis.

To help illustrate each account, the stories will be quoted directly. However, I will not fracture the account into thematic categories as grounded theory coding would do, but instead will interpret it as a whole, working with a single interview at a time (Riessman, 2008). I will reproduce excerpts alongside my own interpretations, as I seek to map the
meaning-making process that happens when a narrative is disrupted by illness. Finally, fitting with thematic narrative analysis, language is viewed as a resource for expressing meaning, rather than the actual topic of meaning.

3.6 Conclusion

This chapter completes the justification for using a narrative research methodology, a discussion which began in Chapter 2. Having presented the methodological foundation of this research, I concluded this chapter by outlining the process by which I will interpret the stories. The next chapter I will present the restoried versions of the original transcripts in Chapter 4, followed by an interpretation of each individual story in Chapter 5.
Chapter 4

The Women Tell Their Stories

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**4.1 Introduction**

In Chapter 3, I discussed the research methodology, and described the process of gathering the individual narratives of the women I met throughout the research. In the following chapter I will introduce the focus of the study; that is, the stories that were generated as a result of this aforementioned research process. The restoried drafts of the initial transcripts are presented as part of a holistic approach, with the aim to recognise them in their own right, with value as they stand alone.

**4.2 The women's stories**

The women's narratives are presented in the order that they were gathered. Before each story, I will briefly introduce the storyteller and the context in which the story took place. This, I hope, will allow the reader to encounter the stories in their own right before reading my own analysis of them. As discussed in Chapter 3, the place (described by Connelly and Clandinin (2006) as "the specific concrete, physical and topological boundaries of place" (p.480)) in which a story is told is linked with our identities and experiences of that particular place. Therefore, I hope to make the experience of the context, or place, in which I encountered each storyteller explicit. I present each woman with a name that I feel fits their story, along with a quotation that, for me, appears to capture the essence of their story. This of course, is only based on my own interpretation of the essence of the story, and it is important to note that this will differ from person to person, based on their own experiences and understandings of the context of breast cancer.
Introducing Caroline

In May 2013, I met Caroline. Before our face to face contact, I knew only the basic details of what treatment Caroline came for each week. The consultant had informed me that she came for chemotherapy (Taxol) once a week for five hours. She had been coming for operations and then subsequent treatment since the beginning of January, 2013.

When I first walked through the door and entered her hospital room, her husband was sitting on a chair beside her and a nurse was mopping up her blood from the floor as her IV had come out. The room appeared very busy. I wondered whether her husband would want to stay in the room whilst Caroline and I spoke, but before I asked, he volunteered to leave. I describe this context to make the reader aware that Caroline was telling her story in a hospital setting, where she had just been bleeding all over the floor. However, as soon as her husband and the nurse left the room, Caroline began to embark upon telling detailed story of her cancer experience. Whilst telling her story the chemotherapy equipment beeped and had to be changed, so we paused a couple of time. We were also interrupted once by a member of staff offering lunch and refreshments, but Caroline asked them to come back later.

Caroline

"The way I am now, it's completely day and night compared to how I was before"

The Diagnosis

It all came completely out of the blue for me, as I'm sure it does in most cases. The build up to this is the fact that I am a professional, a global director of a big company, and the only woman in the world who does this role. I've personally achieved a lot in a difficult environment, in which appearance and being strong and powerful is important. So, for me it was all about the whole package and how you present yourself, as I do a lot of speaking at conferences and lecturing around the world. When I got the news that I had cancer I had only been with the company I'm with for twelve months. So my whole world was turned upside down. It wasn't just about having to come to terms with the disease, everything stopped, and everything changed, overnight. I was diagnosed on January 9th and by January 20th I'd had my mastectomy, and my lymph nodes removed. Although I didn't really have a lot of time to get used to the idea, I think I'm a very strong person and I haven't cried over this at any point.
I've been trying to analyse myself a little bit. Whether or not I've accepted my condition, whether I've just compartmentalised it and pretended it's a bit of an irritation, or whether actually I'm coping very well, I'm not sure. I feel more concerned about my job at the moment and whether it will be there when I go back, as opposed to whether I've actually beaten the disease. My husband says don't even worry about your job. But I'm more worried about that, or about my son's fridge not working. But that's how I deal with things. Historically, I pull shutters down in my mind. I'm drinking more than I've ever drunk before and it's a case of thinking that I deserve it. If my consultant said to me, don't have any alcohol with your chemo, then I wouldn't have touched it. I've had a lot of dealings with psychotherapists through my work as a police officer and with child protection services. I've self-analysed myself a number of times about why I do certain things. It's not that I'm giving up; it's more a case of being very practical about it all. I'm not feeling sorry for myself, I feel sorrier for everybody else around me. So if anybody asks me how I am, I deflect the question back to how they are, because I don't want to know about me really.

I think I frighten people with how practical I am about things. My mum doesn't want to talk about things. We lost my aunty to ovarian cancer and my grandma to breast cancer. My sister is now being checked from a genealogy point of view, to see how she fits. She's very high risk at the moment with the scoring mechanism, so the likelihood is she's going to have a mastectomy. And for me, if this doesn't work then that's very practical and that's fine. Just let me know, and I can then deal with it and work out everything. But nobody wants to hear this at all. Mum tells me not to talk like that, and I say well actually I've got to be practical. It might not work. I've just said today, when do you know it's worked? And they said when you've had a scan we'll see if you are in remission. You read so much; I think I have become sensitive to media. Every newspaper seems to be about breast cancer. You know, my cousin who was the same age as me, died two years ago from a brain tumour. And you think well if that's the case, then that's the case. But I wouldn't have another round of chemo, I've already made that decision if it hasn't worked.

This whole chemo thing, you really are in a place of limbo. You have to go through certain procedures, and then have the radiation. You read all these stories where somebody's fighting cancer for all these years and then they die, and you think, well actually, tell me now. So from the point of view of limbo, life is really on hold. I'm not the Caroline who is normally the one who has the get up and go. I have no energy, which has never happened to me before. I used to be able to get up at 4 o'clock in the morning,
get on a flight and come back the same day. Then I'd do the washing, or the shopping on the way home. That's how I've always been, and now I'm struggling to walk or do anything.

Changes in Appearance

My self-image has changed completely. I own very expensive clothes, beautiful shoes and handbags. Now I'm wearing leggings and t-shirts from Tesco. I've got my wardrobe or my uniform that now fits with my condition. Losing my breast didn't bother me at all. But I think what I've done is put myself in a bit of a cocoon, because my world right now is very small. Whereas normally I'm forward facing with a lot of people, now I'm not seeing anybody other than my husband and my close family. It's the same as my hair, I'm not bothered at all, I used to go to the hairdressers every six weeks and spend a hundred pounds a time having colour done. My hair had to be perfect and now I haven't got any. I haven't bothered with a wig, in fact this is the first time I've had a scarf on. From a femininity point of view, I've actually been very accepting of what's happened, to the point where I've actually put weight on. That's unheard of, you don't really put weight on with chemotherapy or when you've got cancer.

What I really struggle with is if you had seen me before, and seen me as powerful to the outside world, dealing with all sorts of issues with the board. But then this happens and I'm so accepting. I accept losing my breast and my hair, and I wouldn't have thought I would have dealt with it in this way. Everybody is surprised I'm not devastated. What I've suggested now to my consultant is to have an elected mastectomy. Although everybody is wondering why I would do that, I think it's a very practical thing to do. I've never worn a prosthesis, it's false and it's not me. They gave me one of the soft prostheses when I was in hospital. Although I looked at it and straight away thought no, that's not for me, I did try it on and went home with it on. But then, I put it away and lost it. I also got fitted with a proper prosthesis, which is a massive mould thing. I wore it once after my son's graduation, and then I thought no. It's the same with the wig; I'd rather not have the questioning stares. This is absolutely how it is. When I came here for my chemo, straight away I went to the wig place round the corner, because that's what you do. I listened to the man build up his story, explaining what they do and why they do it. He told me, before your hair falls out completely, they take little bits off each week, creeping up slowly on the cancer. So I listened, and then went away and tried on all these different wigs. But I thought, who are you kidding? It's not about the money; I could have had any that I wanted. But I don't want it. I'm not a vain person, but every week I had my pedicure, my
massages, facials and hair every six weeks. My husband can't keep up with me and my clothes shopping. I had lost eight stone last year and I've nearly put it back on. I don't know whether it's that I've given up, but it's like I'm a different person now.

Not having my hair doesn't bother me, but it bothers everybody else. Other people's reaction to you not having hair is funny. I went for a meal with my son's girlfriend's mother, and I had to take my scarf off as I get really hot. But she couldn't handle it and said no, don't take it off, not here in the restaurant. Then of course people do stare. I went for dinner the other day with my mum and there was a woman who sat there the whole time staring at me whilst we were eating. If I hadn't been with mum I would have asked this woman if she would like to come and join in the conversation, because she really did get on my nerves. It was so blatant that she turned her chair so she wasn't facing the woman she was with.

Others' Reactions

Everything is very superficial at the moment. Everybody is nice to me and I've seen people I've not seen for years. It makes me think, why now? In fact, I got a text last night from my first boyfriend at sixteen. I'd met him at a reunion last year, and he'd texted me asking if I fancied meeting for a coffee. People don't know how to treat you and it's interesting to look at what people talk about or don't want to talk about. It's like having an elephant in the room constantly, and I'm quite blunt. My mum still finds it very difficult though and is devastated by it all. My dad had leukaemia last year and my mum lost her sister to cancer three years ago. She nursed her, so it's all very raw and real to her still. She phones me now five times a day to see how I am. She'll ask me how I am and when I say I'm fine, she'll respond "You're not fine, you've got cancer!" It makes me think, well, I am fine, so let's leave it and change the subject.

I've actually been very surprised about people's reactions, with cards and beautiful words. Even people I've not seen for years have come forward with kindness. I didn't think people thought of me in that way, I suppose I was so busy with everything else that maybe I didn't make any effort, or I was too busy to see people, or they didn't fit my diary. Yet there has been a kindness of people, and not necessarily just at the beginning, but continuing six months on. It's old news now isn't it? All I can say when I'm asked how I am now is I'm tired. And I think actually that would be so boring to hear that for the umpteeenth time. But for me it's also the ones who haven't made the effort who you thought would have. My husband's sister had breast cancer about five years ago and I was really upset for her. I was obsessed about it. I thought it was really important that she kept a
journal throughout it all, so I bought her a diary. I went to visit her regularly, buying her beautiful nightdresses and clothes for lounging around in after the operation. But she hasn't reciprocated, and I find that quite bizarre. And my brother's fiancé doesn't mention it and doesn't phone me. My husband says maybe it's because of how I act.

Similarly, I have been surprised by my children's reactions. I have two boys, one is twenty-eight, and the other is twenty-four. The older one is training to be a nurse so he is very into the medical side of it all, and understands a bit more. But I'm still his mum. He phones me and texts me every day, asking how I am. But the youngest one behaves differently. When he came home yesterday, I had my sleeve for my arm on, because I have lymphoedema. He asked why I was wearing it, and when I explained that I had my lymph nodes out, he responded "but it's all gone now...they cut it out". But then I thought well actually, that's his way of dealing with it. He's not made any more effort than he did before the cancer, but he's happy and settled, and probably working hard. I just don't know whether he's not taking it in, or he doesn't understand, or whether that's just his way of coping. Again, my husband said it's partly my fault because I've said I'm going to be alright; or rather, I was told by my surgeon that I'm not going to die.

In Limbo

I don't know if I need a kick up the arse, to say come on, get a grip. But this is where the limbo thing is, because if the cancer comes back somewhere else, I'm thinking, how will I handle it next time? It's all very new, a journey I've not been on before. So I wonder if it is me reacting in this way to protect myself by putting myself into a cocoon. But really I seem to be more worried about practical things like whether I will have a job at the end of this, or whether there will have been a massive reorganizational change that I'm not there to be a part of. I'm also thinking about doing a degree. I've paid for everything and got all the books that I need, and this would be a perfect opportunity to do it, but I just can't be bothered. I'm just not me, the normal Caroline who's very organised. There is no ironing, washing and cleaning. When I used to go away, I would remote manage my children. But now the whole thing is completely different. People tell me, don't do this, don't do that. Don't stretch, don't hoover.

I have always been the one who is first in my life. I was the first in my family to go to grammar school. When I joined the police, I was the first woman on my relief. I was the first woman to come back on shifts after having a baby; I went back when the baby was six weeks old. I was also the first one to get to the CID. So it was all tick, tick, tick, always first, and that's how it's been throughout my life. I had a hysterectomy and was
back to work within six weeks because nothing holds me back. But this time, I think, should I go back to work? But the thing is this tiredness. I’d love to be the one where people say you know, she worked all the way through her treatment. You do hear about women who work all the way through treatment. But I just haven't got the energy. I wonder, am I giving up? It's very frustrating.

Creating a cocoon
All my life I have had this ability to compartmentalise, and I'm not saying this is a good quality. However, it's how I deal with things, by making this little world. It's a very small world now, coming here on a Wednesday and going to the caravan at the weekend, because that's what my husband wants. And that's as much as I do. I'm struggling to read, I don't seem to have any concentration. Yesterday I went to bed for five hours just to sleep away a day, which is just not me. And I don't know how to get over this. If I don't, it will be a big reality when they say right ok, you're well. Going back into that way of being will require me to sort out my image, and get back to work mode and working out what I actually want to do. This kind of questioning is constant; at 4 o'clock this morning I was wide awake thinking about work and if there is no job for me how we are going to manage financially. But putting myself into a cocoon is something that has always been there. There have been things that have happened in my past where I have coped by dissociating. The cocoon is a dissociation and my way of dealing with things. I see people in here and I'm just not dealing with it in the same way as them. They're very fragile and frail. But I'm just trying to get on with it. After my mastectomy I was fine within two and a half weeks. The surgery's not that bad, but it's the chemo that I'm really struggling with. The tiredness is constant. Whereas with the surgery, once you've had it you start to get better, the chemo is twelve weeks along with the other cycles I've had either side of it. After this, I've got radiotherapy. And in amongst it all is the uncertainty of whether or not it comes back somewhere else.

Thoughts about the Future
You're a ticking time bomb from now on really. My husband's father came round the other night. He's eighty-eight and it made me think, I don't think I'm going to live to eighty-eight. Then I looked at my mum who's seventy-three, and I thought, I don't think I will live to seventy-three. My husband said to me, you have at least another twenty years, which made me think, that would make me sixty-nine, which is still not old. So I think there's the mortality issue as well, with everything I think about. I wonder, will I ever go
back to work in the Middle East again? I see these older people as champions. I look at
my dad, who had leukaemia and was very poorly, but made a full recovery. But it's not
even though for me to have faith that the same thing will happen to me. I don't think it's that
I'm feeling sorry for myself or that I have a particular sixth sense about the future. Perhaps
it could be an acceptance, because normally I would just fight absolutely everything. It's
not that I want to die. I'm going to be a grandma at the beginning of December, but that
doesn't take the edge off everything.

A Shared Experience
I feel very comfortable talking about things. When I first got diagnosed I approached the
company and said I'd be happy to do a blog throughout this. It's a very male dominated
company, so I thought it would be nice for the whole work force to read a blog promoting
the condition, and how to deal with it. They didn't take me up on it, but I'd like to think
there was some way I could help other people. On the day of my surgery, I was calm and
collected, doing business phone calls right down to surgery. There was a lady in the next
room having the same surgery, who was very upset about it all, and they asked me whether
I would go and sit with her to make her feel comfortable for the surgery. Once again, that's
probably my displacement; I can deal with someone else's upset but I won't deal with my
own. So I saw her off to theatre and told her she'd be absolutely fine and had nothing to
worry about the surgery. I told her very practical things, explaining that she'd have a
needle in the back of her hand and go to sleep.

Dealing with Changes
Like I said, I'm a very practical person. We had some analysis done at work last year with
my team. It was all about team dynamics and how different personalities complement one
another. I came out with what you call a red person, which is probably not the best
characteristic. It means I'm very demanding, and I recognise that normally I am very
demanding of myself. I wish now I could kick myself up the arse, but I don't know how to
do it at the moment. If I could, I'd be the one who's still being organised. Before, I was in
charge of things, and now I'm following my husband's lead. That's something I have never
done in the twenty-eight years we've been married. Now I've handed over my bank
account to him for the first time in twenty-eight years, which means I have to account for
what I spend. I get my spends now, so everything has changed. This is something that I'm
tolerating, I'm bobbing along, but it's not real. It's not me, because normally I would be
demanding and arguing, but now I want someone else to do it. I think the issue is that at
the end of this, I don't know what I'll be, because this is my life at the moment. My whole diary is made up of hospital appointments, physio appointments, and that's it. But at some point, that's going to end and then you've got to try and pick up the pieces. I'm sure I will, but at the moment I can't get my head around it. It's just all about now. I have thought about it, but not in a way of thinking, oh why me? It's never been like that. I've been very cold about the cancer.

I was told by my surgeon that I'm not going to die. Although she said that before surgery, and how she knows that I don't know. For me, I feel that nobody can say that for sure. Because at that stage, she didn't know how advanced the cancer was, or how I was going to respond, or whether I was going to go into remission or not. So those were just words. Just like when I went to get the wig and the man told me it would really suit me, and told me about the special creams he was going to give me to put on my head every night to force the hair to grow; I thought, this is just a sales pitch. I saw it as someone taking advantage of somebody else's vulnerability. I thought, people believe this every day. And you don't need a bloody wig. And I haven't, not because I'm principle based but because I couldn't be bothered. I have no idea why, because from being a little girl I have always loved my hair and had beautiful hair. It was only short, but it was immaculate. And now there isn't any. I feel as though, if something is not me, then I don't want it. So, with the prosthesis, it's not me, so I'd rather be lopsided and me, rather than having something up against me that doesn't feel right. It's false, as soon as my arm brushes against it, I knew it wasn't me. So I'd rather not have it.

When I walk through here and see how people are coping, some are very poorly, and others you see with wigs on and they're just so false. I don't see myself because I'm always looking at other people and their situation. There was a guy who I saw struggling out of his taxi this morning. He couldn't walk and was obviously very poorly with a horrible pallor. I asked him if I could help him into his wheelchair. My husband goes mad at me for always organising everybody else. I get myself into so much trouble with always buying stuff for people, and wanting to do things for others. My husband says, why do you have to do this? I have my sisters' children to come and stay, I cook dinner for my husband's father, making them dessert and something to take home. It makes me happy and I really get a lot of pleasure out of doing things for other people. And yet I don't expect it back, and make excuses for people not doing it for me. Like my son, there is no excuse for him not making the effort, but I think maybe it's my fault because of the way I gave him the news by making it too light a subject.
Uncertainties

My husband asks me, what I will do if I can't go back to work or I lose my job. That makes me really anxious because I have always been in control in that respect; I have always had the financial flexibility to do the things I want to do. If that was no longer the case, I think I would have to get another job, I couldn't possibly stay at home, it's not in my nature. But in this position I see myself in limbo, and in an unreal period. I wish somebody could tell me what to do, to just flick a switch and say right, you can go to the gym now, and Caroline, you are overweight. Caroline, you must stop drinking and give yourself a kick up the arse. Start being practical – get up in the morning, go out for a run, take the dogs for a walk, read some books and do your degree. I would probably be really upset if somebody said it but actually if my consultant said to me no drinking, or you're putting on weight. But he's not. Like I said, last year I had lost eight stone, and I've put it all back on slowly since last October. I've put on two stone since being diagnosed with cancer, which is unheard of. And I know why, because I'm just indulging myself which I hadn't done before. My husband daren't say no when it comes to a glass of wine or a suggestion to go out to eat. But I need someone to turn around and say, get a grip; this is not a pretend world. I say it to myself in my head, but then I can turn it round the other way.

But as I've already said, at the moment I wouldn't want to do the chemo thing again, which has upset people. This decision comes from a practical point of view where I think if it's not worked the first time, then it's not going to work the second time. So I'd rather just deal with the practical side of it. I would rather know what the worst is going to be and deal with it accordingly. I've actually picked all the songs for if I die. I worry about making sure my funeral was nice and that people enjoy it. I even said to my mum that I would like to have a party to celebrate my life before I die. In fact, I had a boob saying goodbye party with my friends and family. I thought it was an excuse to get everybody together. I was even going to order a cake in the shape of a boob, but my mum was going to be there and I knew she wouldn't see the funny side of it. So I held back on that, but it was going to be the icing on the cake shall we say, pardon the pun.

Influence of Early Experiences

Recently though, I have been so tired. My sister is a district nurse and she told me that the chemo is causing it all because of what it's doing to my body at the moment. But then I
wonder, what is it doing to my body, because I've got none of the symptoms that are on the list they go through each week. So I think, well actually, I don't think it's working. As for the tiredness, it's probably lethargy rather than anything else. Or perhaps it's the depression that taking over and caused it. To think about what the future will be is difficult at the moment, but I'm not frightened and I don't think I have felt sorry for myself. I've not cried over this, which is probably an acceptance. I knew as soon as I went to the doctor and saw her face that it wasn't good news. And from that moment on, I have accepted it and had to help everybody else. But my concern is whether it will come out at a later stage. The reason I talk about it all the way that I do is because when I was twelve I was raped, and didn't tell anyone. It was a family member who did it, and I had to deal with the whole of puberty and growing up with this secret. I didn't tell mum until the day I got married. And then we never spoke of it again. I had a strict Catholic upbringing so you can imagine what it was like when boyfriends came on the scene, but she never knew any of this. So I had to make this little world which I've always reverted back to. I refer to it as pulling the shutter down on things so I can cope. And I did cope, because nobody knew. So it's my self-preservation and way of dealing with things. People ask me where I get the strength from, and I think well it's probably because I'm just pushing it all away. I am still on my antidepressants, but that means I then can't have tamoxifen. So that's the next issue. It's something I've been on for twelve years, and coming off them would make me even more depressed. So I just try to forget that too at the minute.

Re-evaluating Life – Who Am I Now?

Going back to the image thing, the way I am now, it's completely day and night compared to how I was before. I've got wardrobes and wardrobes full of clothes and then I think, I'll just wear jogging pants. It's as if those clothes are not me right now. I bought a pair of expensive shoes before I was diagnosed and I haven't worn them since because they just don't seem to fit my image at the moment. It's as if I am trying to keep it all very separate and compartmentalise. In a sense it could be linked to not wanting to mix things here with life at home. I could have had chemo at home but I would rather come here and deal with it, rather than it invading home. So it's all about keeping everything separate, and wearing the shoes now just doesn't feel right. But then I wonder, will it feel right in the future? I've even started clearing things out and giving stuff away. It's about re-evaluation, everything I look at, I think, do I need it, do I want it? And I feel fine about thinking this way, being very practical.
Everything's just died down and almost overnight turned into this tiny little world. When this is all over and if I get the green light, I will have to pick up the pieces and re-create some order and semblance. I wonder, do I want to be the person that I was before, or the person that I am now? It's all very surreal. I think now about support and counselling. I felt quite anxious when I went to see the surgeon and she told me I was doing really well, that everything looked fine, and that she would see me in six months. It was a shock; I didn't know what to do. I think that with the whole cancer thing, there are gaps in your care. You have your own doctor to deal with physical day to day symptoms, then you have your oncologist who has your regime of your chemo, and then there is your surgeon. But then there are little gaps in between, because the three don't speak to each other. So they don't see you as one person. To one person, you're a chemo patient, to another you're a GP patient.

*Role Models*

As I said, my cousin died at forty-six of a brain tumour, and I nursed my auntie in the last few months of her life following a battle with ovarian cancer. They were both very stoic people, never complaining, and they have been my role models. Not like on television, where it's all drama and everyone crying. But my way of dealing with it is to consider all the practicalities of it all. I'd like to think I'm reasonably prepared mentally, and if somebody said the treatment is not going to work, then I'd say right, tell me exactly how long I've got and I'll make plans accordingly.

I'd say my mum still is a significant role model for me. I get phone calls every day and she still treats me as her daughter. Nobody else would get away with telling me what I should and shouldn't be doing. I do consider myself very lucky with my family. I have my brothers, sisters, mum and dad, and a day doesn't go by where I don't speak to my mum. Even when I was travelling round the world in different time zones, I would still call my mum every single day. So that's why I struggle with my boys, when my youngest doesn't get in touch, it's hard. And my husband isn't very touchy-feely like me. I like a lot of cuddles and hugs, a lot of reassurance. Not once since I've had this have I asked my husband whether I look nice. In the past I used to ask all the time, and he would always tell me I look lovely. Even though he always said the same thing, once he said it I felt reassured that I looked fine. So now, I would have thought he would have offered it, despite me not asking. It feels like now the intimacy has gone, and we have become companions. And I miss that intimacy. At work I was very attractive, causing heads to
turn, men asking me for affairs! And now there's nothing, all of that has gone. I just blend in now; nobody would take one look either way.

The Final Stretch

Now I'm on week eight of twelve, so I've got four more weeks. Then I have two more of the big sessions again, the three weekly ones, because I had to stop them as I had an infection. And then I have the radiotherapy, so that will take me up to probably mid September or early October. So that's ten months of treatment in my new world. Then it's the reality of what comes next. Nobody is talking about it, so I don't know if I get another scan or when I get another scan. Do I wait for lumps and bumps to appear, or symptoms to appear? I don't know if I've even asked the right questions. One of the questions is why can't they take my blood now and see if there is anything in it now? Maybe I just need to start pushing myself a little more. Maybe go on a diet and things like that. I feel I am thinking about a lot of things now, and not sleeping. I am waking up and thinking I should be getting out, walking the dog, or whatever it is. I just need someone to give me a big kick up the arse. There are no certainties with any of this, and I am not good with uncertainty. I like being able to work to a deadline, and this is all a bit laissez-faire. But we'll get through it in the next few weeks, September is not far at all.
Introducing Rosemary

Rosemary is a retired lady currently in remission following secondary breast cancer. She attends hospital once every three weeks to receive treatment (herceptin) keeping her in remission. I met her early on a Friday morning in June, 2013, as she prefers to attend hospital at times that are less busy.

When I arrived in her room, Rosemary was sitting with her husband by her side. Both of them were drinking tea and eating toast, and laughing with the staff. They greeted me with smiles and appeared very relaxed. It was immediately evident that Rosemary's husband was going to remain present throughout our encounter, and therefore the nurse went to get me an extra chair. Whilst we waited, we all made small talk and I thanked them for being happy to be part of my research. Throughout our time together, staff came and went, bringing medication, changing chemotherapy and offering drinks. However, Rosemary did not pause from her story, instead inviting them in to join her with her storytelling, with exceptional openness.

Rosemary

"When I do talk about cancer, I approach the subject laughing"

No time to think
Well I've never had really time to think about things because I always worked long hours. I used to work in a library, and we used to work around nine till half seven. I've always been on the move and active, so I never used to sit around thinking. I got diagnosed with cancer for the first time fourteen years ago now. And then it came back after fourteen years. So I really jumped straight into what I had to have done with my treatment without thinking that much about it.

When I went to the first hospital, the first time I had it, they told me straight that I had cancer. I knew they were going to tell me that because there was always a nurse going in and I recognised it was for the people that had cancer. So it was a give-away. I always look at people's faces. So when I was going for a scan, I was looking at all the faces, and I could tell by looking at them that there was a problem. So at that time, it was a case of waiting to hear what I already knew and when the doctor told me I had to have a
mastectomy, I just said fine. The fact that I already knew what I was going to hear gave me a bit of time, so I went back to sit in the car while I was waiting to see the consultant. I had had private health for a number of years, so I called them up to tell them. And they said fine, we'll sort it. So by the time I'd got back to see the consultant I knew in my head that I had cancer and that I was already starting to sort things out. There was a Macmillan nurse there, and she asked me if I wanted her to come to see me at my house to discuss what was going to be done. But, I didn’t want that, because I didn't want someone to namby pamby me and fuss over me. I'm my own self, and I know what I want to do, and I can do it myself. I just like straight talking. And that's the end of it. Of course I wouldn’t like to be told that I only have a certain amount of time to live, but at the same time, I don't want anyone to sit and hold my hand. I am independent and I decide it all. And that is the end. But I knew I had cancer and that I had to have the treatment. And that was fine. I had it all, and for ten years, I just came back for routine check-ups.

Complications and an unexpected return

I'd had scans but they hadn't picked anything up. Nobody picked it up over all those years. In hindsight, I should have really gone into it more myself, and insisted on CT scans, because I had insurance, so they would have paid for it. They were paying for all my check-ups and everything. So I blame myself for not going into it more thoroughly and I just wish I had realised.

Fourteen years after I had had the mastectomy, I found a lump under my arm. I wasn’t looking for it; it just was there when I was drying myself one day. So I went straight to the doctor and told him I had found a lump under my arm. He informed me they usually don't do anything about it straight away and recommended that I leave it for two weeks and then come back to see if it had got any bigger. I told him that I had already had cancer and that there was no way I would be leaving it, and that I had already booked in to see the consultant. So all I really wanted was a referral off him really. When I went to see the consultant, he had a look at it and he said, I think it'll be fine. My response was to tell him I didn't think it would be fine. So he said, don't worry about it, I'll take a sample out of it, which he did right away. He was going away to Wales and he rang me up on the way there to tell me there were abnormal cells in it. So I said no, it's not abnormal cells; you mean it's cancer don't you? I was told to go in the following Tuesday and they would sort something out. So then I had an operation to remove all the cancer under my arm. Then I had CT scans and it showed that it had moved to two bones. My next priority was to get
rid of the cancer in my bones, so I was referred to another consultant, who has been really brilliant.

I have had twenty-four chemotherapies, and then I had radiotherapy, so it's been a lot of treatment. But I have also been told I am HER2 positive. As soon as I found this out, I wanted to know what it meant, and I found out that it means that your cells divide. By having this herceptin every three weeks, it stops the cells dividing. So I'm on that every week, and then I take something for my bones every six weeks. This will be treatment that I will receive for the rest of my life, until it stops working, and then they'll look for something else. I come here to the hospital every three weeks and everyone here is very nice. I'm here, I can't complain, and I feel really well.

Another thing that happened to me before I found out I had this current cancer, was that I had a rupture in the reconstruction. It makes me wish I hadn't had this reconstruction done, it's a flaming nuisance. Although I had the mastectomy I'm not bothered about the appearance, I just feel grateful that I'm here. I was just told you can have it done and I went along with it, but it turned out to be a right mess. Then in addition to all of the treatment I have received for cancer, I had a prolapse in the bowel. I had it before I started, but I couldn't have it done until I finished all my treatment. That was sheer agony, so I got that done as well at the end. So I've had seven operations altogether.

*Life as we know it now*

Before this, I was never really ill touch wood. I've always been well, I think because I've always been busy and on the go. I don't smoke, I've never drunk. I don't over-eat, I eat the right foods. But then I got cancer, so it's really weird. It doesn't add up. I can't say well I should have done this or I should have done that. I tell you what I did though, I had HRT and I regret that. I should not have had that. And I should have had more check up's when having HRT, which I'm a bit angry about. But I was the one who made the decision to have it. So, that's the end of it.

But I'm now in remission. My consultant said I should be in remission next year, and the next year, the year after that, and the year after that, and the year after that, and then we don't know. Nobody can actually say you're cured with cancer. You can't can you? It's dreadful. I regard the cancer as some sort of alien. It's not like a person, but it's intruded on everything. But despite everything, I still do a lot of walking. As soon as I got that prolapse done, I carried on walking. I've got a little dog, and I've got five tortoises! I also look after a stray cat. So I've got to keep myself right to see to everything, because they've got to be seen to. Normal life goes on. I've got to take my dog out and see to all
my other animals. So, it's all got to be seen to. I will continue having scans; I'm having another one in August. And then after that I'm told it's one scan every six months after that. So, I mean, I've got to think myself lucky. Although I was unlucky in one way, I'm very lucky in another way. I'm lucky because I'm here and I've got it sorted.

Overall though, the consultants have been very good and I feel safe. I was told I can have the chemo done at home. But I said I don't want it done at home, because I don't like home and hospital to be mixed. I like them to be kept separate. But I'm happy to be here. As soon as I walked in here, straight away, I felt really comfortable. I thought to myself, right, this is it. And I didn't even think that they wouldn't get on top of it. In my head it was all positive thinking. I've always been a positive person. There's always ways round things, and it's not always black. There's no use thinking the worst. Although quite a few people have died who were coming in for chemo with me, I don't think oh, that'll be me next week because there's no use in having those kinds of thoughts.

Unfortunately, I did feel pain with that prolapse at the end, which really annoyed me. That's why I went to my doctor then, and he kept saying oh wait a bit, and then in the end, three weeks after, I went and I said no, I want this done now. I wasn't putting up with it any longer; it was invading me and my life, preventing me from being able to do anything. I couldn't even go to the shops and I like to do things myself. It was worse than this cancer! But when I got it sorted, I was very pleased with that and I ran in when they sent for me. I don't like it when I'm not in control. Although coming here is fine, I accept that it's something that I have to do and that it's keeping me here. It's keeping me able to do the things that I want to do. You know, we like to go to the parks and that, and take my dog. I walk too much. In the end I can't walk anymore. I was always running about at work, I've not ever been a sit down person.

Maintaining normality
I didn't lose my hair because I had that ice pack during chemotherapy, which was terrible. I wore it on my hands and feet, but the worst one was my hands. I was frozen the whole way through and had to have all these blankets all over me. But I thought, I have to put up with it through mind over matter. I thought about the positives; it stops your fingers nails coming off, your hair falling out, and it stops you getting pins and needles, which you can get from that drug that I was having. I came every week for it and had it done twenty-four times. The nurse would put conditioner on my hair, and then I'd rinse it off here, and go home with a hat on, still wet, and then let it dry itself. I didn't use a dryer. So since physically I looked the same, nobody really knew that I had cancer round about where I
lived, because the sure giveaway for having cancer is that thing on your head, or wearing a wig. To everyone who saw me, I was just the same Rosemary, walking about with a smile on my face, with my dog, and thinking oh yeah, everything's fine. And when I looked at myself, I look the same because I didn't lose my hair. So I think not losing my hair was really important. I know it's fine, flyaway and stupid hair but I think the first giveaway is your hair. Of course some people try it but can't cope with it, but I'm a devil for punishment and I'm not a pain person. I don't feel pain.

So I think you've just got to carry on as normal. You've got to try to at least. When I think about the future, I don't know. Cancer is something that you don't know. I'm seventy now, so I'm looking on eighty as something to aim towards. In order to carry on as normal, I continue to do things like walking; I always like to be active. And I love driving. I love going places in the car, drive for miles and then come back. When I'm in the car, I know I'm in control and I know I'm ok. For me, normal is just being like I was before, and going and doing my own shopping. For two months after I had that prolapse done, I couldn't go to the shops or anything. I couldn't go in the car and I couldn't do anything like lifting for two months. So that was a bit annoying. But, I kept walking. Walking filled my day in a bit until I could get back into the swing of it and get in my car and off I went. And that was it.

This cancer that's come back now is the most aggressive because it's just gone into the two bones. I asked them if they could cut it out! But despite it all, I'm still here. I've been given this stuff to help my bones. I've just started on that. I'm trying to eat the right things, which I've always done anyway. I've always been nine stone. I've been nine stone since I was twelve. I went up a bit while I was in hospital and wasn't on the go. But then it's come down again as soon as I've started doing my normal things. I don't watch my weight, I just carry on as normal. But we don't eat after tea-time. I was never allowed to when I was little. We might have a biscuit and a drink, but that's all you could have. You had to just do as you were told, and not have anything at night. My mother always said it sits heavy on you at night. But I can't wait to get my breakfast in the morning, I love cereal. So we come here and have our breakfast. Coming here is not a big deal. We say we're going to the hotel again, and when we get to the corner we say here it is. It's here and now, your life's here and now, you've got to live it here and now, haven't you?

I've just sent for some clothes. They came yesterday, so I'm looking forward to that! I'm looking forward to undoing them, and they'll all be the wrong sizes, I'll have to send half of them back. I focus on day to day stuff, so all of this about cancer just goes over my head. My consultant said he couldn't believe my reaction. When I walked in,
when I had all those tests in hospital, my consultant had such a stern face and I thought, what's the matter with you? They all had dead stern faces. And he said, I'm afraid it's a mastectomy. And I just said well I've been onto the insurance company already and they said they would sort it. So that's when that nurse was kept round, holding my hand saying don't make any arrangements now, have a think about it and talk about it. But to me, there was nothing to talk about. I've got cancer, and talking doesn't alter it, let's just do what needs to be done. Although I was being very practical, somehow, I couldn't really realise that I had cancer. I just felt as if I was being carried along. I wasn't linking myself to it. And even now I don't really think about it.

**My family**

I've got three daughters. But our Jane, the oldest, she's very good. She'd take me anywhere if I needed it when I started this. We deal with things as a family by sort of laughing it off. When I first got diagnosed, it was upsetting for everyone because nobody had it before. But when we came here, it was comforting and a weight was taken off. Our Jane, she's funny; she's a teacher and she's bought me that many bouquets of flowers. But she's had her problems too, she had a brain tumour. And then there's Julie, the bossy one, hands on hips, telling you what to do. But they know I won't do what they tell me to do. They won't interfere because they know what I'm like; I'll do what I think I should do. They know that we can sort it because we always tell them, don't worry we'll sort it. Just keep trying to keep as well as you can and normal as you can is what you've got to do. And that's what I'm trying to do, just keep on top of everything. And then nobody knows any different.

**Other people with cancer**

My mother had cancer. It was years ago, she was only sixty, and they couldn't do anything then. But it's just one of those things isn't it? I'm just another person, there's loads of people get it, and so why am I different? You can't pity yourself can you? So with my reaction to the mastectomy, it wouldn't have bothered me if I hadn't had reconstruction, because to me, it's not important. I'm not going to go round with a bikini on, my life is a lot beyond that. Things like that were never really that important to me anyway. I've never pampered myself. But I never go out without mascara on. I like my face right, because I had two car accidents, and both times I didn't have any mascara on so I put it down to that!
I know a lot of people who have had cancer at work, and I've always said to them, well don't worry about it; they'll soon get you right. And a lot of them they have. But it sort of hits them like a tonne of bricks. They go to pieces because it's a death wish. But you don't want people to think that about you. And sometimes I think, have I got this thing? What actually is it? But I have to go into it in depth- like with that HER2 positive, I had to ask what does this mean? I had to know exactly what it means.

Fighting spirit

I've caught a lot of robbers. When I'd just had that mastectomy done, I went to Sainsbury's to do my shopping. And I saw this car coming down. And I knew then what they were doing. I have an instinct for knowing what people are doing. And as they were coming down the hill I thought, they're coming for my car and my bag. So I slammed the boot of my car down and I had my bag over my shoulder. Then this lad got out of the car, and he marched over to me to get my bag. He didn't get my car keys because I had them in my hand. But he came back over to me, demanding to know where the car keys were. I told him that there was no way he was having them. So he dragged me over to his car. I was put over these two lads knees and I was screaming at them. Everybody heard me at Sainsbury's who was coming out, so people began running up to the car, so these lads got in the car and drove off with me hanging out of the car. All my trousers were ripped, but I was alright. I was lucky again. I can't leave things if anybody does anything to anybody else, I have to jump in and try to sort things out. And it's the same with cancer, it's this thing that you've got to beat, and it's no right to be there. And what is it anyway? There's no other way round it but to try to just beat it.

The integration process – looking to the future

For now, I'm alright and I'm happy. I like seeing people, and I always like to go where there are lots of people. I've always been with lots of people. When I was having that chemotherapy, there were four of us and we would talk our problems over. But like I said, there's quite a few that have died. It's very sad because last time I saw them they were quite well. With cancer you go downhill fast. But instead of worrying about those kinds of things, I tend to just worry about my car, and whether it has any dents in it. I think about things like that and it takes you off thinking about cancer. I'll start thinking about my tortoise instead and why it's not eating. And then I'm so worried about my tortoise that
I can't even think about myself. Overall, I feel like I'm doing something positive. And I feel like I have nothing to worry about because I'm here being sorted. Although I've got to come every three weeks for it, that's fine. I think of the fact that some people have diabetes and have to have injections and things every day, so it's no different for me having to come here every three weeks. I don't like that word remission because I don't really know what it means. But when I was told I was in remission for this year and next year, I just laughed and said what about the next year?

My consultant did say that he isn't that bothered about me. I have a blood test every time I come and they can tell a lot with the blood, with anything that is going wrong. But it's just stopping it from settling anywhere, because if just a little bit gets into your blood, then that's it. But it's not in any of my major organs which is good. So I think all in all, that I'm fine. I'm still exactly the same. It didn't affect me, like they say it might if you read up. They said you get this, that and the other. But I didn't. I come here for the toast, and the tea. We arrive at eight o'clock when it's quiet and then we go home. Then we're not in anybody's way because some people will be here longer. And it's busy sometimes in the day. Before I used to be here longer too, we used to come at eight o'clock and get home at about half five. But it just had to be done, that one day. I was just glad to have it really; you've got to be thankful and positive about it doing its job.

Nobody knew the second time that the cancer had come back. It wasn't that I didn't want people to know, I just don't like going into a prolonged conversation about cancer. Next door, the lad over the road, he's got it, he comes here. He's only thirty-odd him. He knows, and we have a laugh. But people do tend to look at you funny sometimes. But I'm still exactly the same. When I do talk about cancer, I approach the subject laughing, instead of having seriousness about it. They all knew at the library that I'd had it last time, but nobody bothered. I wasn't any different with them because why should you be? I just laugh about it.
Introducing Linda

Linda is a lady in her forties. When I received an email from the hospital confirming that Linda would be happy to meet with me they gave no information about what treatment she was receiving, so I knew nothing about the person I would be meeting.

When I met Linda in July 2013, she was having her weekly chemotherapy, which she informed me was for secondary cancers. As I entered the room where Linda was receiving treatment, her husband was sitting by her side on the computer and the nurse was present. I asked her husband if he would like to stay in the room, and he said he would but that he wouldn't say anything. However, as time went on, he became a very present part of the conversation, adding his views and opinions. Whilst the story below is Linda's own words, his words played a part in what she said. At times throughout, Linda would disagree with his memory or the meaning he had made from an event – as I observed their interaction, it appeared as though, through their discourse, she was able to make clearer in her own mind the meaning she had made throughout her experience of cancer.

During our encounter, hospital staff came and went, and each time Linda was sensitive to the fact that my recorder was on and she instantly asked me to turn it off whilst she paused in her storytelling. She was very emotional and tearful on a number of occasions, and commented on the fact that this is not normally how she reacted. She recognised that talking in this type of context felt different, but she was unsure why.

In the beginning

It started off roughly in 2002. I was diagnosed with breast cancer in my right breast, and I had to have the lumpectomy. This was then followed by a course of chemotherapy, and then radiotherapy. After that I had five years of tamoxifen, a hormone therapy treatment. My reaction to it at the time I think was absolutely devastation. Everybody thinks they're
invincible and that it’s never going to happen to them. So it was a real shock to the system. I couldn't believe that it was happening. 

Although I've had secondary cancer now several times, each time with my treatments, it is a shock. Then something just happens and I just overcome it. For some reason, something kicks in and I think to myself, right deal with it. It's not going to get the better of me. All the way through this, I have had my good days, and I have my bad days. But, I have more good days than I do bad ones. Every time, it takes me I would say around a week or so to get my head round it. I actually continued with work. I wanted as much normality as possible and work played a big part in that. I worked for a bank, a personal assistant, for a sales team, so although it was fast paced, it kept me focused.

This carried on for the five years; I was taking tamoxifen and everything was hunky dory. Eventually I was told to come off the tamoxifen because after the five years it does more harm than good. Then unfortunately, two years down the line, I had a lump in my neck. So that was a real blow. That time round second time, I thought that was it and that there wasn't going to be any chance of survival. That was going back five years and things have come on so much now. It gets better and better. But with this diagnosis I had to have a course of radiotherapy. And my consultant said that the prognosis was good because it hadn't gone anywhere else, it was very isolated again.

Reacting and adapting

When I first found it I was actually sitting at work at my desk. And I'll never forget that day, because I was just having my lunch, and I just happened to put my hand on my neck. I thought, what is that? It was just a boulder and I hadn't previously felt it. But I think it's something to do with your glands or something try to fight it. So then it swells up or something, but I'm not quite sure. Despite having to go through radiotherapy again, I did come round but I must admit, that second time I did think that was it. I absolutely freaked out that time, more so I think than the first time. It was a shock to the system. You only ever hear when people say that you get it second time, it's a bleak outlook.

We were referred to a different consultant who had a different philosophy, and who specialised in breast cancer. He told me straight away that it wasn't life threatening, and explained what we had to do going forward. And thankfully that was all sorted. I don't think I was on any hormone therapy then. There was no trace of it anywhere else. Then it must have been two or three years later, it was a really bad winter and I fell over actually on the ice. When I fell, I got a really bad pain; it was a discomfort more than anything. I knew that something wasn't right and I knew it was more than just a fall and a pain. I had
that appointment with the doctor about a week later and I mentioned it to him. And he said well we've got to do the scan anyway. So I had the scan and it picked up tumours in the sternum, and some spots on the lungs.

_A balancing act_

So how did I handle it that time? I think I was shocked again. But I was more hardened to it and I thought ok, what do we do now? Everybody handles it differently and some people just completely crack up. But for me I thought ok, what are we going to do now? I had to go through chemotherapy, and I had several scans along the way. Throughout this period, treatment was looking good. And because this is hormone related, when I've finished my treatment, I've had to go on courses of hormone therapy. So although the chemotherapy seems to work, I then go onto a course of hormone therapy and after a period of time, the cancer seems to kick in again. We're talking small nodules.

For the last three years now, it's still isolated in the sternum and the lungs. But they just seem to grow slightly. So for the last three years, on and off, I've been on different courses of chemotherapy, and then onto different types of hormone therapy - chemotherapies then hormone therapies. My consultant is trying to get me into remission so it stabilises and it's steady. But I've not reached that. Last year I was on a drug, a tablet form of chemotherapy. I was on that for a year and I thought I had cracked it. I'd been having three monthly check ups and things seemed to be at bay. Something within me just felt as if I had cracked it this time. But then I had a scan, and my consultant told me that the nodules had slightly increased in size again meaning I had to be taken off that drug.

I must say this time round I think I must have been more shocked. I think I must have gone back to stage one, to when I was first diagnosed. Because this time, it took me longer to adapt to this news and to come round to it. It maybe could have been to do with the fact that I had begun to adapt again to a more normal life, because when you're having tablet form of chemotherapy, it's different to coming here every three weeks. Coming here to hospital brings it all back to you. But when you're on the tablets, it's not the same as when you're sitting here having chemotherapy. I have to have the cold cap as well, which is a real pain.

_Working out the jigsaw puzzle_

So it's been really mixed emotions. Up and down. I feel in the middle part of this jigsaw puzzle that has taken around twelve years. Each time I have just thought well what do we do now? How do we deal with this? Although we could always get a second opinion if we
wanted to, we feel confident with our consultant. He always says to me, what's right for one person isn't necessarily right for somebody else. He was hoping that these chemotherapy tablets were going to last a lot longer than they did. But as he said, you just don't know and it is a case of trial and error. What might be right for one is not necessarily right for someone else. So each time I just get on with it, and deal with it.

I see the experience as being like a jigsaw puzzle in a way, with all the pieces fitting together so we get the outcome, which is the remission. You go so many steps forward and then back again and it's like ok, you go forward and you put that piece of jigsaw in and you think ok well move onto the next piece. And then oh, you can't find that piece, so you've got to go back again. That's the way I look at it. At the moment, I feel as though I'm still somewhere in the middle. I've sort of got the outside of it, but I've just got to find those last few pieces. The outer bits to me are related to dealing with it. And then the inner bits are actually finding the solution. So I feel like I have got the outer bits sorted. But I'm just finding the final pieces of the jigsaw puzzle so I can finish it off and get the outcome that we want.

Other people's perceptions
People say to me that they can't believe that I'm going through what I'm going through. I mean I don't normally cry. And I think it's just when I'm talking to people for the first time, I suppose it hits home more. But when I'm speaking to people on a daily basis who know what I'm going through, then it's a bit different. And I sort of make light of it. They say I can't believe what you have been through, what you're going through now; it's amazing that you have the attitude that you have. To hear that, it does make me feel good and I'll always say if someone's just been diagnosed, that I would be willing to speak to them, and give them some sort of support if it helps them. My friend Tracy had breast cancer and then she was diagnosed with secondary cancers. She says I am her inspiration. But to me, that's just me. I mean when I'm at work not everybody knows. The people that do know comment on the fact that I'm in work and carrying on like there's nothing wrong with me. And I say that mentally and physically, there isn't really anything wrong. It's just something that's there that we need to sort out.

I think when you hear the word cancer, you just think of people being really poorly and you see a lot of cancer patients without hair. I always said that if I lost my hair, that's what would upset me. When I was first diagnosed that wasn't what upset me. What upset me was the fact that I was going to lose my hair. It's vanity I suppose. But if I ever felt poorly going through treatment or anything like that no one would see me in that light.
Not being seen to be sick is a freedom. I want it to be private. That means a lot to me. So when they mentioned that I could have this cold cap that helped me quite a bit to deal with things. It meant I could carry on as normal without people looking at me and thinking she's got cancer. I would have hibernated for however long it took for my hair to grow back. There was one time with one of the chemo's that I could have lost my hair, even with having this cold cap on, because it was quite a strong chemo. So we went out and spent four hundred and fifty pounds on a wig that's still sitting in my wardrobe.

It's just a pure vanity thing with me. I am happy to talk to friends and family about cancer, and I'm quite open about it. At work I keep it pretty low key, but only because normally when people know you've got cancer, they're forever pandering and I don't want that. I want normal, I want as much normality as possible. Basically I've only told people that need to know.

A new approach

For me currently this time, I've actually taken time out of work and I'm just trying to rest a bit more. I'm just taking a different stance on it this time. My husband was worried that I was going to sit at home and fester and start panicking. When you're on your own you start thinking things, but I haven't. I've actually quite enjoyed the time off. So I've changed in that approach. Perhaps I'm not thinking about it as much as I have done previously when I've gone into work because it was mind over matter and I could focus on work as opposed to everything else. I mean don't get me wrong there's not a day that doesn't go by that I don't think about this. But at the end of the day, I'm in the hands of my consultant and I've just got to get on and deal with it. There's no point in dwelling on things.

There was one time when I took on a second job. So I'd finish working at the bank, and then go to my other job from six till ten and not get home till eleven o'clock. I took it on because I was finding that I was coming home and I was beginning to think about things and start to mull over things. And I thought, oh no, I can't be doing with this. Then somebody said to me do you fancy another job? And I thought, yeah go for it! And it actually did work, and stopped me having so much time to think. It started off as a Christmas temp, but because I kept opening up all these accounts for them, I ended up being there for three years. So I had two jobs for three years, whilst having treatments in between. But it served a purpose. Plus I brought up two kids as well.

For a long time, I'd say I had this one approach where I was always thinking I need to get back to work, I need to do this, I need to do that. Things have changed at work.
though, and I know stress is not good for anyone. But when you're going through something like this it's important to put myself first. The trouble is that the people who did know what I'm going through see this exterior that I present, with hair all nice and make up on, smart and a bubbly personality, and maybe they think, is she really suffering from cancer? I portray this sort of image.

As a family, we don't let the cancer rule our life, we control it. So we've just been away for two weeks on a cruise and I've delayed my treatment. My consultant said in the scheme of things it's fine. We will work things around a holiday. We dictate and say right this is what we're doing. Previously, this is not something I would have done. From day one I would have said no to delaying treatments. We did that actually half way through, when I was diagnosed again. We were due to go on holiday and we cancelled, because I said I can't go on holiday thinking I've been diagnosed again. I wouldn't have enjoyed it. At that time, I wanted to get on with it and start the treatment. Now though, I've changed and I thought, as long as it's not detrimental then maybe it would be ok to go away. I said to my consultant, if I need to have this treatment then I'll have it, but if you think that missing one cycle and delaying by three weeks isn't really going to make a huge amount of difference then I'm having my holiday. So that's what I do now. I just live for today and enjoy life. I think I have a different approach now as to when I was in the first half of the in the jigsaw.

When I was younger

I think I've hardened and become more assertive. I think when I first started off I was going into the unknown, so perhaps I was more timid and more frightened of what was ahead. I've accepted it and dealt with it and I just get on with life. I think now I know my body more than I ever did before. I feel more in tune with any aches and pains, compared to how I was before all this happened. For example, when I had that fall, my husband said oh you've just pulled a muscle. And I thought no I haven't, I know something's not right. So I just think that over the years, if somebody has gone through this for as long as I have, you just get to know your body more, and your inner self. I suppose I'm just more aware now. Before I was diagnosed, I thought I was invincible. I would have thought, me, cancer at thirty-six years of age? That's unheard of. It wouldn't happen to me. I eat healthily and I exercise – within reason! You just never think it's going to happen to you and it has made me have a totally different look on life. Nobody's invincible and it could happen to anybody at any time.
I did smoke, when I first got diagnosed. I had been smoking for maybe ten years on and off. I wasn't a heavy smoker, but as soon as I was diagnosed, although they said that wasn't anything to do with the breast cancer, I stopped it. Before that I used to party a lot. I worked in London, so when we'd completed on a deal we used to party all night after work and go home to bed for a couple of hours and then get back up and get on the train back to London again. That was when I was in my twenties, and I'm a lot older now, but those days are long gone. I do look after my body a lot more now, and respect it a lot more now. I think in those days you didn't hear so much of alcohol having some connection. But over the year you hear that eggs aren't good for you, you can't do this or that, and I always remember my breast consultant who did the operation said to me, do everything in moderation. Do not change your life style. I've always kept to that and every consultant has said the same thing.

At the end of the day I know people who have never drunk, never smoked, have exercised and they've ended up with breast cancer or some other form of cancer. So at the end of the day, if you're going to get it, you're going to get it. Well everybody's got it anyway; it's just a case of it being triggered by something. Whether it's something to do with all those years of partying and late nights is something I will never know. We've just been on a two week cruise, and we've had a lovely time. I've had some drinks, but I haven't got up in the morning and thought oh I've got a hangover. Those days are gone, because I've got to look after my body now. So it's just everything within moderation now. I bought a dog last year because I thought that would be a good form of exercise. She's a shihtzu so she's only little. We've got a fair sized garden, so I just walk her round that! To me it's another form of companionship also. My husband is at work and the kids are out at work, so she's sort of helped me in some way.

Re-evaluating life

Each time, when you have your scan and you go for your results you think please, as long as there's some sort of stability, either remission or static. If it was just stable, then I'd be happy with that. But when you get told there's a slight increase in growth again, then it certainly knocks you back. But you've just got to get on with it and deal with it and not let it take control. And that's what I do. I think if somebody had said to me prior to being diagnosed, that you're going to be going through all this for this amount of time, I would have said no way. There's just no way I would have dealt with that. But it's surprising how your mind just takes over and says no you will. I'm not saying that's everybody's philosophy, everybody is very different. But I think it makes you realise more how
precious life is. And you do more things. And you don't take things for granted. I hear people at work who say for example, 'oh I've got a sore finger', and I just think, get a grip. People are signed off work for a week because they've got a cold. I've been coming into work throughout the whole thing. I know that's my decision and my choice, but this experience makes you wake up and see life for what it is. You've just got to grab things and enjoy life.

I do think I've changed. We talk things over together, whenever there is something on my mind. We could be sitting there one evening and we could be watching television and something might just click in my head and I'll say to my husband, I need to discuss this. And then we'll put the world to rights, and then get on with it. Having the staff here throughout everything has been amazing, I can't fault them at all. It's good to know you're dealing with the same people each time, you build up a relationship and you're in your comfort zone. They know you and you know them. The treatment and support that you get here helps immensely. The fact that everything here is time boundaried helps me personally. The waiting all day would be difficult and the whole thing could have been a different scenario.

I've always listened to that consultant who did the operation at the very beginning. I have asked if I need to change anything in my lifestyle, and I have been told no, continue with everything in moderation. And, the other two consultants have always said that. Just live your life. Look after yourself, and remember to do things in moderation. And that's what I do. You hear of these people who take all these juices or these fruits. Whether that has any huge effect, I don't know. But that's not me, I'll carry on with what I'm doing. Maybe in the past, when all of this started, if people had said why don't you try this or that, I may have done. A friend of mine has got this juicer and she recommended I give it a go. She told me about black carrot juice, which you can only get from Turkey or something. But I try different things from time to time, and then just swing back into my routine.

I do read things on the internet and think oh. When there are things that are written about in the media, I have to talk about it. All three of my consultants have said do not read things and do not go on the internet because all you hear of are the bad things. You never hear the good things. But they should share the good things too, because for people going through this, it gives them some sort of form of hope and support.

Even though I know I shouldn't read these things, I have done it recently, probably because I'm at home. I think these days, when you compare it back to when I was first diagnosed in 2002, it was new to us both then. But we read more about these drugs now. So I just keep an open mind and a positive one, and just get on with it each day and deal
with things as and when anything happens. That's all you can do. I don't spend time now thinking, what if this happens or what if that happens. If it happens, we'll deal with it.

_The experience of talking_

I can normally talk about it, but it's still emotional, for example when telling a stranger. When I'm talking to somebody for the first time I suppose it just makes it a bit more raw, but then I eventually get into the swing of it. I don't understand really why it's so hard talking to someone I don't know, I can't get my head around that one. Perhaps sometimes you don't really know what you're thinking. The thoughts are there, but when you actually start talking about it, how you actually do feel, and how your emotions run, it's when you actually go into the nitty-gritty of it. But I feel we're getting there with the jigsaw, I'm going all over the place at the minute but I hope it's piecing itself together. Sometimes I lie in bed and just visualise this puzzle.
Introducing Judy

Before meeting Judy to hear her story, I had met her two weeks before when I was attending the hospital to meet with another lady. It was a very brief introduction from one of the members of the hospital staff, and I stayed with her and her husband for only a matter of minutes. I thanked her for her willingness to meet with me, and she told me that she had a lot to tell me.

Two weeks later, in late July, 2013, I met her again for our planned encounter. She was in for chemotherapy, but she had decided to wait to receive it until after telling me her story. Her husband said he would make himself scarce whilst we spoke, so Judy and I were left alone.

As Judy told her story she was breathless and wheezing, but she took her time and told me that she was happy to carry on nonetheless. There were several times throughout our encounter that staff entered the room, and I turned off the recorder as they were there for some time. The first time, a nurse came in to take Judy's temperature and blood pressure. Then, at another point, in the midst of her narrative flow, her consultant came in and they discussed the goal of returning back to work.

"I don't see myself as brave, I just see myself as someone who has to go through it"

Where it all began

I will start in March 2008 when I was first diagnosed with primary cancer, which was breast cancer. I then had a choice. I could have just had it taken off completely, or I could have had a lumpectomy. They didn't offer me reconstruction at the time and I'm not sure that I was bothered about that to be honest. Maybe now I should have done but at the time they didn't push it and I didn't push it, because I was just devastated and wanted to get over it all. So I had a lumpectomy. At the same time they did that, they put a dye in to see if it had spread to my lymph nodes, which unfortunately it had. So ten days later I had about eight lymph nodes removed and about six of them were cancerous. I had the operation, and then I had the chemotherapy. And after the chemo, I had three weeks worth of radiotherapy.
The worst thing for me about the chemo was that because it was a mixed one, I decided to use a cold cap in an attempt to stop my hair falling out. But despite going through the process of wearing it, my hair still fell out, but not all of it. And I'm just wondering now if that had anything to do with my cancer mets in my brain. They said at the time that the cold cap causes the chemotherapy to miss out your head altogether because it's so cold, meaning it sort of bypasses your head. And that's why the hair is not supposed to fall out. So now I'm left wondering. It's one thing wondering though, but nobody else has said anything to me, so I don't really have an answer.

I had to go back for mammograms. I think the first two years I went every six months, and then it was once a year. It's all a bit fuzzy. I would go and see my oncologist at the time, and when I went for my check ups everything was perfect apparently. The mammograms were fine and my oncologist would just ask me questions, and examine me, and then say right, this time next year. It's funny because my current oncologist said that now I'm under his care, he will keep hold of me and keep a close eye on me. And I will probably have to go back to see him more regularly than I did before because obviously it's secondary cancer.

What happened next
In November 2010, I started coughing incessantly and it just went on forever and ever. I went to all sorts of people, including people who specialise in ear, nose and throat people. I had CT scans, but nobody knew what it was. Then somebody looked down my throat and my nose, and said, oh, your throat looks a bit manky. It was all green and so for a while I just thought it was that. Eventually, I got an appointment to see a surgeon who specialised in ear, nose and throat. He was going to do me a fundoplication because one of the theories was that that acid reflux that was making me cough. What they do in this procedure is sort of bypass some of your stomach and it's supposed to stop you coughing.

I was due to have the operation on a Tuesday, and the Thursday before, I went in for a pre-assessment to make sure I was ok. Unfortunately, I'd been off work ill that week because, my stomach was so bloated that I couldn't walk up the stairs. I didn't know what was wrong with me, but I knew something was definitely wrong. I went to the doctor, and I was dehydrated; I hadn't eaten and drunk for a week. He just took one look at me and told me I wasn't going anywhere. I was told to go to my local hospital A&E, and get to the bottom of this. I always say that doctor saved my life. That's how I feel.

I don't drive, but luckily my husband had taken me after work, so he was still with me at the hospital. We went to A&E and I was in that hospital for three weeks. Well, I
was there for a week initially, and I was constantly being sick and generally just very unwell. That week was a bit of a nightmare. Then I wanted to go for this fundoplication, still thinking there was nothing else wrong with me. I told the staff that I wanted to discharge myself, because I needed to go and see my doctor. When I arrived to see him the same thing happened again. He said you won't like me for what I'm going to say, but you're still not well. He told me I needed to go back to hospital in order to get to the bottom of what this is. So they sent a private ambulance for me. Meanwhile, my husband had gone back to work thinking I was having this fundoplication. I ended up back in hospital for another two weeks, and by the end of the second week, they had got to the bottom of it.

My world falling apart
I had a scan. It was an ultrasound around my stomach and heart area. Then the next thing I know, all these people showed up and I had this emergency procedure. They pumped ninety mils of fluid from round my heart. One of the nurses from upstairs was holding my hand and crying, and I'm thinking why is she crying? She's being a bit soft. But she knew about the cancer and I didn't. Then this head doctor came round and told me that things had been seen on these scans. He still wouldn't tell me it was the C word, but it was obvious.

The nurses hauled in the surgeon who had done my lumpectomy and removed my lymph nodes, because they knew I was one of his patients. And he was so blunt with me. He just said, yeah you've got cancer. It was awful. I thought my world had fallen apart, because what they said to me was that it's not curable but it's treatable. So I thought that's it, I'm going to die. My husband came, and the Macmillan nurse had been round too. When my mum and dad came she talked to them in the patient's room and told them that I had two weeks to live. And they'd said to my mum and dad, yeah we'll get one of the hospital beds, and we'll put it into your house in the living room next to the fish tank. In other words, I could just quietly slip away. I only found out all of this afterwards. At the time I just knew that they had said I had two weeks to live. But here I am a year later.

Dealing with the news
I'd rather scan over it all because it was just such a nightmare time. They couldn't find veins; I had canula's in my groin, in my neck, all over the place. Even my foot. They couldn't find any veins and they kept asking for blood. But they could never get any blood out of me. It was crazy. I just kept thinking, oh god, why me? I had a few tears as you
do. But then after that, I felt like I had an outer body experience looking down on myself. It's like I didn't believe it was happening to me because it was just so surreal. I thought no, this isn't right.

At one point just before I left, the head doctor came round and I thought he was a bit rude to me actually. My husband had been asking what can we do, and wanting a second opinion. And the doctor said, well you need to be able to walk out of here. And I responded, how can I walk anywhere? I was chained to the bed literally. Well that's how it felt to me. I was hooked up to an IV, and I had a catheter in which meant I couldn't go to the loo. So I had a catheter bag on one side, and then on the other, they stuck a drainage tube in my back. I don't know if it was to kidneys or maybe liver. But they did that in my bed. It was a junior doctor who did it and I felt like they were hacking me to death. But obviously in their eyes it was an emergency, they had to drain all of this fluid off me, which was what was making me cough. Like I said, I had nine hundred mils of fluid from my heart, and it was all red with blood in it. But then I had this other fluid as well which they were trying to drain off me. But I had some sort of epileptic shock or something. I was freezing to death but I was sweating and shaking. It turned out that they were flushing too much liquid out. To me the whole thing was botched up. The other vivid memory was being sick constantly and everyone trying to get to the bottom of why I was being sick. But they couldn't.

My husband, when I told him, was absolutely devastated, as you can imagine. We were all in tears. But my husband went home and slept on it, and he said I'm not having this. I'm going to get a second opinion on this. So that's when he did some research and found another consultant, who agreed to treat me. We came in on the Sunday and he sat down with me for about an hour with my case notes from 2008, and went through everything. He just filled me full of confidence, which hadn't happened before. He just said yes, we'll do this and we'll do that, we'll get you on chemo, we'll get you on this drug, and we'll get you in remission. He was just so positive and I thought, maybe I'm not going to die in two weeks after all. It was a feeling of going from down there, to up there.

They were all diagnosed at the same time, apart from the brain tumours, which were found about a month after my chemo started for my lungs, liver and bone. I was still being sick, and nobody could understand why. But something clicked in my consultant's head and he said I think it might be brain tumours. So they got me into the ward. The day after I'd had the scan, I was told that I had brain tumours, and at that time I thought it was that that was going to finish me off. It was something about the way I was told. My consultant said that he could get me in remission from the neck down. But because the
tumours are on the inside of the brain not the outside of the brain, there's only so much
can do. I had the whole brain radiotherapy and I think that's why my hair's gone like
this. Because I had that big helmet thing on, I was told that it might take a while to come
back properly.

My consultant does a lot of networking, so he sent me to another hospital that does
things in a different way, and has had good results. Rather than it going over your head
and back again, the gama rays come at you from different angles, so they can get it to a
hairs width and pick up everything. I went back last Monday, and was told the results are
fantastic. One's disappeared, some have shrunk and some have stayed the same. Hearing
that news felt great. This consultant said he didn't think it was a controlling factor in my
cancer anymore. But my consultant here still does I think, but I'm not sure. So that's really
my potted history. It started in July time and it's been about a year now.

Making sense of things and getting well
I said to my consultant, I know this has only just been found, but have I had this for some
time? He was a bit noncommittal because he said if you have had it for a while, it wouldn't
actually make any difference. In other words it still would have been secondary, so it still
would have been cancer mets and the prognosis still would have been the same. The only
difference is they're hitting me once with everything, whereas if it was a year or so before,
they would have strung it out a bit longer. That would have made it less intense. I feel like
can't really get to the bottom of everything though, because nobody will say anything.
People keep saying to me, you know you ought to take it further, but at the moment I just
want to get well. Just let me get well and then I'll think about it.

I mean, I'll never be 100% well. Well means to me a reasonably normal life. My
husband has been very good and he reads all sorts of things on the net. Some of it he
shouldn't and some of it he should. My doctor always tells him off and says he shouldn't
read things on the net, but he doesn't just read forums and stuff, he also reads the actual
medical journals. He tells me that people can live years. He says don't go thinking you're
going to die tomorrow because people are living up to ten years. Fortunately, my type of
cancer, or my body DNA reacts well to the drugs that I've been given. I've
had no bad reactions to anything and everything's been good. So I can only touch wood.

I got very reliant on the steroids, so my main thing is to try to reduce that reliance.
I couldn't come off them for a while because they were keeping my headaches down. But
now this Avastin is to stop the headaches, which means I can get off the steroids. So
hopefully, my moon face will go down, and I won't be getting as chesty and out of breath.
So my main aim is to start moving again and get my weight down. I have never, ever been this heavy in my life. I was ninety-five which really was my heaviest. And I've just gone up to ninety-seven. I can't understand it because I'm hardly eating anything. What I am eating is obviously the wrong thing, chocolate and stuff. I mean there was one point when I had to go onto Megace, which was to get my appetite back because I was eating nothing. It's not back properly but it's better than it was. I'm still not right though. Last night, I did steak, new potatoes and salad. I had a little bit of steak, gave the rest to the two dogs, I had one new potato, and I had two cherry tomatoes. That's it. That's all I had.

I'm hoping that this Avastin will kick start me now, because really I want to get back to work. I've been off for a year and they've paid me all the time I've been off which is very good of them. But they're not going to pay me 100% forever. I'm a legal secretary and was in charge of four people. I want to get back, for my own normality as well. I want to talk to people during the day. I'm just watching Judge Judy all day and sat in front of the telly. And it's not good for me. At the moment, I've spoken to my bosses at work, and when I do go back occupational health will be coming to see me. It'll be phased hours, until I get back to normal strength, doing what I normally do. I hope it doesn't take that long but we'll just have to see. I mean I don't want to put too much pressure on myself though, my doctor has said don't go back until you are ready. It's just one step forward, two steps back. The aim is to be as normal as I can be.

*The unknowns of the body*

I have got secondary cancer in my lungs, my liver, my bone and my brain, and these are the four places that it could go when you've had breast cancer. It's still called secondary breast cancer but I've got all four and any one of those will kill me. I've spoken to my husband about it and he says oh we're all going to die, we could get run over tomorrow. And I say, yeah but I know vaguely, that one of those four will kill me. It's either going to be liver cancer, lung cancer, a brain tumour, or brain cancer.

I've not asked how long I've got. Because for one I don't think they know. Even if they did know, I don't know if I would want to know. If I don't know, I'm in blissful ignorance. If I did know, then it's like a death sentence round your neck. It's like it's there all the time, it's like an inner demon. Instead I would rather shove it into the back of my mind. I'm quite good at that, and I've done this since 2008. I only bring these thoughts forward when I need to. It took a while to be able to do that, but I've trained myself quite well. I don't know how, I think it's just part of my personality. I've just been able to deal with things like that.
Sometimes, when I see people die of cancer, I'll think, am I kidding myself here that I'm going to last five years when it might be five months? And isn't it funny that now I've got my cancer re-diagnosed, everybody I know is dying of it, or has got it. One of my friend's recently got diagnosed, and then a friend's mum has got it. And you just think oh god, I can't get away from it. It's weird. There was a gang of us at school – there were five girls, and about five or six lads, and we all used to hang around together. And out of the girls, three out of the six have got cancer. You just think, it's no good this.

Invaluable support

My mum and dad have been wonderful. They live just around the corner so they come and see me every day and they're really concerned bless them. But I've still got them around you know. I probably appreciate my mum a lot more than I used to. If she wasn't there to help me I don't know what I'd do without her. I need her to help me do things round the house, but it's emotional help as well. She's always buying me flowers and stuff like that. And my dad's wonderful, he's done my garden again this year, he's a bit of a gardener. So I've got all these nice colourful flowers when I look out of the window. My Mum does all my ironing for me, because I can't do anything. I can't even bend down. If there's something on the floor I can't pick it up. I can't walk upstairs. I'm hoping that these things will get better as I come off the steroids and I get stronger. I'm on bone strengthening injections as well. But my case is so complex because of the fact that I have four secondary cancers. I was in an ambulance going to hospital for breathlessness and pain in my chest. And when I was going through my history with the paramedic, she was going on to her second page of writing. She said to me, my you've got a complicated case. And you know what, it is. But because it's happened to me, I don't see it as complicated. I just say oh no, what now?

My husband has been brilliant because he puts everything into perspective when I have a little wobble. I do every now and then, I'm not superwoman. Cancer is on the telly all the time. On Emmerdale at the moment, Brenda's got brain tumours and she'll say things that make me think. It's a bit difficult. But my husband says well, everybody's different. You can't think that her case is the same as yours. He says that a lot to me. Everybody's different. Everybody reacts differently. Not only have they got different cancers, they've got different reactions to chemo and stuff. Another thing was Bernie Nolan dying. Everything was a parallel to me; same age as me, same cancers as me. She died. But then my husband says, yes, but, she was on a nebuliser thing for three months so
she was obviously you know, very, very poorly. So what I think was the exact same as me isn't in fact.

*Illness and personality*

I think it's all to do with personality. I think some people are going to be able to cope with hearing you've got months to live or years to live. Other people can't cope. I don't think I'd like to know. When the time comes, my overactive imagination will tell me anyway. I personally think it's going to be my lungs that see me off, because I'm breathless all the time. I just have a feeling. I can't walk up the stairs. But it's just my guess and you don't get any prizes for guessing. I have to keep my imagination in check. If I didn't I would just die a thousand deaths.

I'd like to think I've always been a nice person. I've always been a caring person, but I'm certainly a lot softer these days. I cry at the drop of a hat, and I think that's a lot to do with this. You get into this sort of emotional state that's always there in the background. I could cry at something on the telly like a little girl falling over. A man crying will set me off. I've always been emotional. I just think it's made me more so. When I've been at home in the day, I see all those adverts on the telly. Well the animal ones, I have to switch over. I can't see a dog being abused, or anything, even if I'm watching something on that channel, I've got to switch it over. Everything has been heightened emotionally. You also appreciate nature and animals more. I am watching a lot more nature programmes and gardening programmes.

*How others see me*

I find it good to talk, to put everything in perspective in your mind. I don't normally like talking about personal things with strangers. My brother died twelve years ago and my doctors sent me to see somebody about it because I was in a bit of a state. So I went to see a counsellor and I just hated it. I didn't think I was getting anything out of it. I know some people like to talk. And funnily enough I don't mind talking about cancer. But what I did do was on my Facebook I deleted all of my casual friends and just kept my close friends. I tell them everything about what's been going on. So I get a lot of support from my close friends. I unfriended all my casual acquaintances because I wouldn't want them to know anyway. But with my close friends, I now feel closer to them funnily enough through telling them. It's nice because they bump me up and say oh you're wonderful and you're so brave. That does annoy me a little bit though, because to me, I'm not brave. I don't see myself as brave, I just see myself as someone who has to go through it. I have no choice.
If anybody else was in the same position, they'd just get on with it in the same way that I do. I get a bit upset with the word brave, because I feel like it's a bit condescending. I know they don't mean it to be, but that's the way I feel. And I've stopped saying now oh I'm not brave. I just don't bother. If that's what people think, then let them think it.
Chapter 5
Analysis

Organisation of Chapter 5

Introduction
Analysing the stories
Reading across stories
Conclusion

5.1 Introduction

This chapter presents an interpretation of the stories from Chapter 4, using a narrative analysis approach. Section 2 below presents possible interpretations of each story that arose from my own experience of each encounter, combining my reflections from the original face to face encounter, with interpretations developing throughout the process of transcription and subsequent restorying. The chapter closes with a discussion of possible links between the stories, synthesising salient aspects across each story. It is important to acknowledge at this point, the richness and fullness of the stories presented in the previous chapter. Whilst all the women interviewed had initially been given a primary diagnosis of breast cancer, the stories they told to me represent experiences of very different illnesses. As discussed in Chapter 2, when I contextualised breast cancer, secondary breast cancer has different physical symptoms, and likely a very different impact on the meaning a person might make of their illness. Consequently, I am analysing narratives of different illness experiences. Moreover, my own re-presentation of the stories will undoubtedly offer musings, questions and hypotheses that differ to another person. However, the very approach to the research is to value throughout the typically 'feminine' concepts, such as intuition, tacit knowing, and 'felt sense' (Etherington, 2004), which undoubtedly lead to varying interpretations. Consequently, perceptions will clearly depend on my own position at the time of analysis. This will be discussed in more depth in Chapter 6.
5.2 Analysing the stories

5.2.1 Analysing Caroline

Caroline starts her story describing her professional life before being diagnosed with breast cancer, implying the experience of disruption of her working identity:

"I've personally achieved a lot in a difficult environment, in which appearance and being strong and powerful is important...When I got the news that I had cancer I had only been with the company I'm with for twelve months. So my world turned upside down...everything stopped, and everything changed, overnight."

On the surface, this description reflects a story of living in chaos, as she experiences what Mathieson and Stam (1995) refer to as 'disrupted feelings of fit', identifying the discrepancies between her former healthy life, and her life that has now been revised by illness. Some of these discrepancies clearly arise from disruptions to her busy routine of work and travel, although one could posit that perhaps there is a fear of looking past the present disruption and into the future, as there is difficulty predicting the future of her illness:

"This is where the limbo thing is, because if the cancer comes back somewhere else, I'm thinking how will I handle it next time?"

If we consider narratives as bound by and constructed in relationships with various individual people, Caroline's chaos and identity crisis can be understood on a socially constructed level. With regard to illness, Caroline speaks at numerous times about family members who have died from cancer:

"We lost my aunty to ovarian cancer and my grandma to breast cancer...My cousin who was the same age as me died two years ago from a brain tumour."

By making sense of her own current experiences in the context of the death of her family members, the 'old Caroline' is lost in limbo:

"Life really is on hold. I'm not the Caroline who is normally the one who has the get up and go."

There is a sense of Caroline being alone; before the diagnosis, her world was big, and busy, but then it shrinks and she is alone. As she tells her story, it is as though she is finally put in a situation where she can think about herself, and in doing so appears to move through a personal journey of searching for a way out of the limbo she is in. Perhaps
her way of repairing the damage that illness has done to her life journey and her destination, is to reflect upon her life previous to diagnosis. This is fitting with Frank's (1995) metaphor of losing a map and destination, with illness being seen as a shipwreck. Whilst Caroline hints to a powerful and self assured identity prior to cancer, she appears to have lost the map for this particular journey trajectory, and she wonders about her old narrative and identity:

"...do I want to be the person that I was before, or the person that I am now?"

Here, Caroline appears to be engaging in biographical work, in terms of foreground and background: the person who she was before being diagnosed with breast cancer moves to the background as she reflects upon who she is now. Alongside this, there is a vein of detachment running throughout the centre of her story, again relating to the theme of uncertainty that appears to impact upon her whole narrative. Caroline refers to the image of a cocoon as she reflects on this detachment:

"It's how I deal with things, by making this little world...coming here on a Wednesday and going to the caravan at the weekend...And that's as much as I do."

An example of the detachment can be seen in Caroline's reaction to self image; throughout her chemotherapy treatment, she chooses jogging pants instead of her corporate wardrobe perhaps as a way of keeping her past life separate to cancer. Moreover, there is a sense that life is going on without her, as implied by the following quote:

"I seem to be more worried about practical things like whether I will have a job at the end of this, or whether there will have been a massive reorganizational change that I'm not there to be a part of...will I ever go back to work in the Middle East again?"

Despite acknowledging this detachment, she explains that she "just can't be bothered". One possible reflection is that this cocoon of detachment is a way of coping with a future of disruption and uncertainty.

Caroline expresses isolation, offering examples of her sons not wanting to know about how she is, alongside losing the intimacy with her husband. Reflecting on this, I wonder what came first; Caroline's dissociation, or the isolation she appears to be experiencing. Either way, as I listened to Caroline, I hear a need for her to share her story as perhaps she had been unable to with those close to her. This makes me wonder how individuals negotiate identities with those close to them. Speaking openly to families and friends is one approach, but often families do not communicate freely (Mathieson & Stam, 1995).
Caroline does not conceptualise her need to talk explicitly, but the imagery of newness and enormity she uses to describe her experiences seems to imply unexplored territory:

"It's like having an elephant in the room constantly...It's all very new, a journey I've not been on before."

Returning once more to the concept of narratives being bound by and constructed through relationships, perhaps her focus on practicalities can be understood as a legacy of her aunty and cousin, whom she viewed as stoic people, never complaining or overdramatizing their situation. However, perhaps that this stoicism relates to her difficulties dealing with the disrupted feelings that she makes apparent in her narrative. Caroline appears torn; on one level she speaks of trying to analyse herself, but on another level, she reflects upon her natural response to questioning as one of "deflect(ing) the question back to how they are, because I don't want to know about me." Perhaps this fits with her desire to be stoic like her family. Therefore, although her self-narrative has shifted in its trajectory, she appears in 'limbo' between remaining stoic versus opening herself up to explore her new reality. Again, this is reflected in uncertainty:

"...if I get the green light, I will have to pick up the pieces and re-create some order and semblance...There are no certainties with any of this, and I am not good with uncertainty."

The concern about uncertainty is reflected by the shock she experiences when her surgeon told her she would not need to see her again for six months. The negative experience of such events could be understood within an account of selfhood, in which her purpose and sense of direction has become lost.

Body image and changes in appearance are also discussed at points throughout Caroline's story:

"My self-image has changed completely. I own very expensive clothes, beautiful shoes and handbags. Now I'm wearing leggings and t-shirts... my uniform that now fits with my condition...Losing my breast didn't bother me at all...It's the same as my hair...I haven't bothered with a wig."

On the surface, there is a discrepancy, as Caroline explains how she used to attend hair appointments every six weeks, and now she has no hair, and will not wear a wig. Caroline relates this change in attitude to acceptance:
"From a femininity point of view, I've actually been very accepting of what's happened, to the point where I've actually put weight on...I've never worn a prosthesis...it's not me."

Interestingly Caroline uses the phrase "it's not me" in relation to the false prosthesis, and also the wig. This comment again hints at discrepancies: she suggests an awareness of knowing what is not her, but statements such as "at the end of this, I don't know what I'll be" hints at uncertainty. Caroline reflects upon the fact that she has "been very cold about the cancer", linking again to the disconnection and cocooning she uses, perhaps as her way of coping. However, the result of this reaction appears to be internal conflict, and difficulty engaging with an altered sense of self that no longer fits with the wardrobe and appearance of her former self. I wonder if for Caroline, her weight gain gives voice to a body that has also lost its sense of self and feelings of fit. The weight gain could in fact be perceived as a symbol of the cocoon that Caroline speaks of, offering protection. Whilst Caroline relates this change in self image to acceptance, a further interpretation is one of separation: keeping the healthy former body and appearance separate. One could also interpret it in terms of transformations of identity, as Caroline changes her appearance to adapt to a new sense of self. However, I wonder how much this interpretation fits with the image of a 'cocoon', which suggests protection and evasion of change.

Caroline's descriptions of getting a wig and prosthesis offer an example of how she relates her experiences to a displacement and disconnection from the world she finds herself in. In the below quote, there appears to be a conflict between social expectations of wearing a wig and prosthesis in order to regain normalcy:

"I saw it as someone taking advantage of somebody else's vulnerability...And you don't need a bloody wig...I feel as though, if something is not me, then I don't want it."

For Caroline, concern for retaining some form of control over her appearance appears more important than conforming to social expectations. Her use of the word "vulnerability" appears to hint at what she is feeling underneath the stoicism that she is attempting to uphold. Perhaps one way of understanding the discrepancies that occur between how she has always approached appearance and how she approaches it now, is in terms of a threat to her identity. Although she may not know what current norm is, perhaps her way of expressing herself and her disrupted sense of self is physically: from her weight gain, to her refusal to wear a wig or a prosthesis.
To conclude, Caroline's story is one of disruption, whereby her old narrative no longer suffices. This aligns with vocabulary suggested by Mathieson and Stam (1995), as an alternative to the more traditional psychosocial research: disrupted feelings of fit, renegotiating identity, and biographical work. Whilst Caroline reflects upon the fact that she is "just trying to get on with things", there is a sense throughout her story that she struggles to imagine life getting better:

"in amongst it all is the uncertainty of whether or not it comes back somewhere else...you're a ticking time bomb."

As Paul Ricouer writes, "we learn to become the narrator and the hero of our own story, without actually becoming the author of our own life" (1991: 32). With this statement in mind, my reflection of Caroline's story is one of searching for a new 'hero' within her story. The original 'hero' of a professional, with an immaculate appearance, no longer appears to fit with Caroline's current sense of self. Therefore, the issue is how to renegotiate a new identity that fits with the existential crisis that she has been forced to face, with the tone of feeling stuck resonating throughout her narrative. The telling of her story could be viewed as a vehicle for making sense of her changing sense of self, and an openness to begin the journey toward change.

5.2.2 Analysing Rosemary

Rosemary's narrative begins from a stance whereby dealing with the cancer itself appears as the main concern, with the initial 'illness meaning' seeming to be one in which illness is seen as a challenge (see Lipowski, 1970). When told by her consultant that her cancer had returned, she recounts the following reaction:

"I really jumped straight into what I had to have done with my treatment without thinking much about it...My next priority was to get rid of the cancer in my bones."

This quote implies a sense of agency over the situation, with Rosemary's narrative at numerous points resonating with the 'restitution narrative', referred to by Frank (1995) as a narrative about movement away from and back toward health in the future:

"This (herceptin) will be treatment that I will receive for the rest of my life, until it stops working, and then they'll look for something else."

Such quotes reflect Western medicine's emphasis upon diagnosis, treatment and cure, as Rosemary focuses on returning to health, rather than reflecting on the experience of illness. Rosemary does not appear to conceptualise her experience in terms of disruption and
changes in sense of self, as seen in many cancer narratives (Mathieson & Stam, 1995), but instead focuses on fixing what has broken down. Frank (1995) notes that fixing requires a mechanistic view, with the puzzle being how to get things working again, fitting with modern society in which mysteries are understood by turning them into puzzles that are assumed to have an answer or solution (ibid). Rosemary appears to take this stance when making meaning of her illness, with her goal being to understand and solve the problem:

"I have also been told I am HER2 positive. As soon as I found this out, I wanted to know what it meant."

I see Rosemary's narrative of her experience as made up of two themes: one of maintaining control, and the other of striving for normality. Striving for normality is a thread that runs throughout Rosemary's narrative:

"I've got to keep myself right to see to everything...Normal life goes on...Normal is just being like I was before."

In this, Rosemary hints at her narrative being as similar as possible to what life might have been like if breast cancer had not intervened, relating a normal life to caring for animals, perhaps seeing this as a focus for making meaning. Frankl (1966) in fact noted that suffering has the potential to lead to meaning found through, among other things being receptive to others and to the environment. Often Frankl's ideas are summarised in one basic concept: suffering is more bearable if it is meaningful (Collie & Long, 2005) and for Rosemary, perhaps meaning is found responding to and caring for those that she loves. This is something that she has achieved as a constant throughout her cancer journey, with one possible interpretation being its relation to her self-worth and sense of purpose.

Rosemary strives for a narrative in which change does not play a part, even with her appearance to the rest of the world:

"Since physically I looked the same, nobody really knew that I had cancer round about where I lived."

In relation to the puzzle analogy, Rosemary's focus is on presenting an unchanged appearance to the world. Despite receiving chemotherapy, radiotherapy, a mastectomy and reconstruction, Rosemary still looks the same to other people, something that she recognises as being of great importance to her. In terms of appearance, her body shows an affinity to restitution in the sense that it still appears as a healthy body. This allows
Rosemary a sense of control, enabling her to carry on as normal. Despite this, there is somewhat of a contradiction in her narrative:

"Although I had the mastectomy, I'm not bothered about appearance, I just feel grateful that I'm here...it wouldn't have bothered me if I hadn't had reconstruction, because to me, it's not important."

Although she recognises the importance of maintaining a 'normal' appearance, at the same time, she feels that appearance is not important to her. This can perhaps be understood in terms of what Reinharz describes as "the complex process of the construction of reality" (1981: 82), rather than as 'discrepancies'. As I re-read portions of Rosemary's story, I draw a possible conclusion that although she is not concerned about her appearance per-se, her 'normal' appearance is symbolic of the self-image and identity that Rosemary holds onto:

"To everyone who saw me, I was just the same Rosemary, walking about with a smile on my face, with my dog, and thinking oh yeah, everything's fine."

Consequently, body image and appearance appear to represent how things were prior to cancer.

A further theme of Rosemary's mechanistic, restitution narrative is that of agency and control:

"I'm my own self, and I know what I want to do, and I can do it myself."

She takes the reins and forces herself into the here and now:

"Your life's here and now, you've got to live it here and now, haven't you?"

Whilst she has been forced to take the role of a sick person in the sense that treatment, tests and results form a part of her narrative language, from this, she suggests she is in control of how she continues to live her life.

Only when Rosemary begins to reflect upon the genesis of the cancer does the restitution narrative appear inadequate. Frank (1995) posits that when a narrative takes a mechanistic viewpoint of illness, then the question of origin is taken over by the focus of solving the puzzle. In contrast to this, Rosemary questions the genesis of her illness:

"I've always been well...I don't smoke, I've never drunk. I don't over-eat, I eat the right foods. But then I got cancer, so it's really weird. It doesn't add up. I can't
say well I should have done this or I should have done that...I had HRT and I regret that."

Tennen and Affleck (1999) (cited by Collie and Long, 2005) identified causal attribution (i.e. adjusting one's beliefs about cause) as a method used to adjust situational meanings after disruptive events. In the above narrative, the importance of having an answer to the question of the genesis of the illness is evident, as Rosemary strives to attribute a cause to her illness, which perhaps relates to her need for independence and personal agency. Even with respect to attributing a possible cause to HRT, she takes ownership of the choices she made:

"I was the one who made the decision to have it. So, that's the end of it."

Rosemary's reflection upon what she gains from driving is somewhat anomalous to her overall narrative tone of agency and control:

"When I'm in the car, I know I'm in control and I know I'm ok."

Placing this statement in the context of Rosemary's focus of restitution, in which she emphasises feeling well and being in control, a further discrepancy is revealed. In the above reflection, Rosemary may be subtly implying a lack of control. Frankl (1966) posits that suffering is made more bearable if it is meaningful, and for Rosemary, perhaps meaning is made by viewing illness as something to beat in a mechanistic way. However, I wonder if it is possible to maintain this illness meaning fully throughout breast cancer. Frank (1995) describes a restitution narrative as one where the 'normal' trajectory remains intact, and for the most part, this is something that Rosemary portrays, perhaps suggesting a view of the illness as somewhat banal, using terms such as "it" and "this, that and the other" rather than specific labels when referring to cancer and its symptoms. However, this mechanistic view of cancer as something that can be controlled appears to be difficult to maintain at times, as seen in the following excerpt:

"Although I was being very practical, somehow I couldn’t really realise that I had cancer. I just felt as if I was being carried along."

From Rosemary's narrative, her 'normal' appears to be one whereby she is in control; however, she expresses a sense of being "carried along" in her cancer journey. Moreover, whilst she does not appear to relate herself to a cancer diagnosis, contrastingly, she engages with terms such as 'HER2 positive', in order to know exactly what is happening. This split is perhaps one of self preservation, whereby Rosemary only engages with cancer
to a certain degree, in order to maintain her focus on normality. The discrepancies that appear at times in her story imply an awareness of the impact that breast cancer could have on her 'normal'. However, perhaps to engage with an alternative narrative would disrupt her otherwise strong restitution narrative that she is familiar with, leaving a 'narrative wreckage' (Frank, 1995). Therefore, she allows herself to be carried along, maintaining control by doing research into her illness, and focusing her energy on retaining normality.

This interpretation fits with the image of Rosemary as a fighter, striving to retain her sense of self. Often a 'positive' attitude is expressed through military metaphors (Lupton, 1994: cited by Willig, 2009) which instruct patients to fight and not give up, and this fighting spirit is one which Rosemary herself introduces:

"I've caught a lot of robbers...I have to jump in and try to sort things out. And it's the same with cancer, it's this thing that you've got to beat, and it's no right to be there."

This statement implies a maintained sense of agency and control. This imagery of battling is again utilised in the description of breast cancer as an alien that has intruded and must be fought:

"I regard the cancer as some sort of alien. It's not like a person, but it's intruded on everything."

The term 'intruded' again appears to let us in on a moment of recognition that the cancer has invaded her life and taken some control away from Rosemary. At this point, she appears to relate to Lipowski's (1970) 'illness as enemy' meaning category. However, she then manoeuvres her narrative back to the dominant plotline of maintaining normality, stating that "despite everything, I still do a lot of walking."

Although Rosemary follows the restitution plotline of a return to health, she gets vague information about her future and what it holds:

"My consultant said I should be in remission next year, and the next year, the year after that, and the year after that...and then we don't know."

Her response to this uncertainty is to look toward the age of eighty as an aim; perhaps by confronting her mortality, she maintains a sense of agency. As I reflect upon Rosemary's words, I wonder if this is her way of engaging with the situation, rather than trying to escape it. This 'serviceable narrative' (Willig, 2009) appears to offer Rosemary a sense of acceptance which may function as a way of coping with death anxiety, posited by Yalom
(2008) as something that most of the time is repressed and excluded from our everyday experience.

Finally, Rosemary's narrative appears to acknowledge the meaning of an experience such as cancer lies precisely in its meaninglessness (see Willig, 2009); things happen without meaning or purpose. Showing acceptance and engaging in a mechanistic way with what needs to be done to fix her body, may be her way of living with the fact that, as posited by Heidegger, we are thrown, without choice, into the conditions of human existence (see Cohn, 2002). Willig (2009) notes that "trying to make sense of the senseless should not prevent us from living with and in spite of it" (2009: 188), and there are intimations throughout Rosemary's story that her perspective is one of acceptance of the meaningless and randomness of existence:

"I'm just another person, there's loads of people get it, and so why am I different?"

Therefore, perhaps Rosemary's own meaning-making process revolves around accepting the randomness of cancer, and irrespective of this, maintaining her life as it was prior to her diagnosis.

5.2.3 Analysing Linda

Linda begins with a story of diagnoses and treatments, stating specific details such as the date she was first diagnosed. Despite significant disruption from cancer, her story often implies a wish to take on a restitution narrative similar to Rosemary. Linda therefore appears to engage with the battle of two narratives, one of restitution, and the other a story of renegotiation in the face of reoccurring disruptions, as expressed in the below excerpt:

"My reaction at the time I think was absolute devastation. Everybody thinks they're invincible...so it was a real shock to the system."

Here Linda perhaps shows a disruption of meaning and earlier beliefs, as she experiences a sudden awareness of mortality; she is not invincible. However, Linda responds by returning to a plotline of restitution (Frank, 1995), looking towards fixing the problem and overcoming it:

"Although I've had secondary cancer now several times, each time with my treatments, it's a shock. Then something happens and I just overcome it...I think to myself, right deal with it."
How women with breast cancer chose to 'deal with it' varies, but for Linda, at least in the beginning, dealing with it means focusing on normality:

"I want normal, I want as much normality as possible."

Moch (1990: cited by Arman & Rehnsfeldt, 2003), when considering turning points that occur in some women after a breast cancer diagnosis, mentioned 'identifying meaning', which is reflected in purpose of life and an awareness of the shortness of life. Within Linda's narrative, keeping things as they were before breast cancer appears to be one of the ways in which she makes meaning from the illness, along with keeping herself busy, which may be related to her desire to find purpose. This is shown through her approach to working:

"There was one time when I took on a second job. So I'd finish working at the bank, and then go to my other job from six till ten and not get home till eleven o'clock...So I had two jobs for three years, whilst having treatments in between. But it served a purpose."

Linda's choice of the word 'purpose' suggests the importance to her sense of self to maintain purpose in her daily life. One could posit therefore that at times Linda's story follows the restitution plotline outlined by Frank (1995), reflecting a desire to return to a time when life was 'normal', with purpose being related to maintaining the life she experienced prior to cancer. Although she is 'sick' in the sense that she has an illness, for a period of time she also worked two jobs and raised a family, creating an image contradictory to an image of illness.

When considering how Linda makes meaning of her cancer experience, her concept of cancer as a jigsaw puzzle is of interest:

"I feel in the middle part of this jigsaw...Each time I have just thought well what do we do now? How do we deal with this?...I see the experience as being like a jigsaw puzzle in a way, with all the pieces fitting together so we get the outcome which is remission. You go so many steps forward and you put that piece of jigsaw in and you think ok well move onto the next piece."

Linda speaks of wanting to "get my head round it", using the image of a jigsaw puzzle, and perhaps retaining an underlying assumption that a puzzle has a solution. When the consultant states that achieving remission can be a case of trial and error, this reality is
juxtaposition with a jigsaw puzzle with a solution. Such conflict may cause a struggle to find meaning, and Linda's decision to work two jobs, perhaps reflects avoidance:

"I took it on because I was finding that I was coming home and I was beginning to think about things and start to mull over things. Then somebody said to me do you fancy another job? And it actually did work, and stopped me having so much time to think."

This avoidance of thought implies a lack of what Arman and Rehnsfeldt (2003) refer to as a 'turning point' associated with encountering the disease and accepting the challenge of suffering from a possibly terminal disease. At the time of our encounter, however, there was a contrast to the original sense of avoidance; Linda's approach had shifted. One might understand this in terms of ongoing treatment; if there is no 'after treatment', then perhaps the restitution plotline is unrealistic. Linda's story highlights the fact that a chronic sickness journey is one of ongoing renegotiation of positioning oneself in the world. This contradicts with the traditional 'sick role' posited by Parsons (1951a; 1951b), whereby getting well is the only considered outcome. Initially, Linda recalls wanting to keep life as it was before breast cancer, denying the potential for change. However, when she tells me her story, she explains she has taken a different approach to things:

"For a long time, I'd say I had this one approach where I was thinking I need to get back to work, I need to do this, I need to do that. Things have changed at work though, and I know stress is not good for anyone...I've actually taken time out of work and I'm just trying to rest a bit more. I'm just taking a different stance on it."

Within this, there seems to be a sense of Linda transforming her engagement with her experience of breast cancer, signalling a passage into a new approach. One clear transformation is a higher prioritisation of herself and her needs, as she changes her life routine. Although she comments that perhaps she is not actually thinking about it as much as she has done previously, towards the end of her story she does recognise changes that have occurred in her:

"I think it makes you realise more how precious life is...You don't take things for granted...this experience makes you wake up and see life for what it is. You've got to grab things and enjoy life."

Furthermore, Linda recognises how she has dealt with far more than she would have expected to have the capacity to cope with:
"I think if somebody had said to me prior to being diagnosed, that you're going to be going through all this for this amount of time, I would have said no way. There's just no way I would have dealt with that. But it's surprising how your mind takes over and says no, you will."

From perceiving an undesirable threat that was "a real shock to the system" Linda's narrative implies transcending limits and expectations. She describes an inner strength that takes over, giving her an ability to continue, despite the ongoing threat of cancer. Coward (1998) posits that this transcendence could lead to "an increased valuing of self...to savouring of the small moments in life" (p.167), as suggested by Linda as she reflects upon valuing life more as a result of experiencing cancer.

Perhaps one way Linda comes to making meaning of her cancer experience is by developing a greater appreciation of life. This process of transformation however is not a linear one, with adapting to the news always being a difficult process that takes time. I wonder if this difficulty can be traced back to the puzzle metaphor that Linda appears to rely heavily on when describing her approach to cancer, whereby there is potential conflict between viewing cancer as a puzzle to be solved versus the transformations that Linda recounts. From her narrative, Linda seems to move between engaging with change and acceptance, and then switching back to the jigsaw puzzle, with remission as the goal. Taylor (2000) views the process of transformation as consisting of different phases and levels, with the final stage transforming tragedy into an appreciation of the illness. Whilst Linda appears to move beyond an avoidance phase, Taylor's phase of 'appreciation' and 'embracing' of cancer is one that may not fit easily with an approach that has an end goal of remission.

Moving now to the concept of 'remission', and how Linda engages with it, there is an overall sense that her story is continually disrupted by diagnoses and treatments:

"Despite having to go through radiotherapy again, I did come round but I must admit, that second time I did think that was it...You only ever hear when people say that you get it second time, it's a bleak outlook."

Throughout her story there are regular disruptions to her "normal life" and her goal of remission. Frank (1995) discusses the modern existence of a 'remission society' in which the achievements of medicine allow people to be effectively well, but not cured, and Linda implies in her narrative, a desire to be a member of this society. Again, Susan Sontag's (1978) metaphor of illness as travel arises, and appears to fit with Linda's story. We travel
between the kingdom of the ill and that of the sick, and Sontag writes of the remission society as belonging to neither, so remain in a permanent visa status. Although Linda had not achieved remission at the time of our encounter, there is still a sense of her belonging to something similar to this visa status, as seen in the following statement:

"I say that mentally and physically, there isn't really anything wrong."

Linda's words imply that she does not see herself as sick in the normal sense, hinting at the fact that maintaining an appearance that hides her illness helps to avoid full entry into the kingdom of sickness. When discussing the benefits of not losing her hair, Linda reflects:

"I always said that if I lost my hair that would upset me...It's a vanity I suppose. But if I ever felt poorly going through treatment or anything like that no one would see me in that light. Not being seen to be sick is a freedom. I want it to be private."

Maintaining an appearance that hides illness means that Linda does not have to change the story that she presents to the world. There is however an issue with telling a story of "carrying on as normal" as they may be left with a disintegrated story and a 'narrative wreckage' (Frank, 1995), if a person's perception of normality ceases to be. If this occurs, it poses the question of how new meaning will be found. There appears to be an importance for Linda to promote her identity now as being the same as it was prior to her cancer experience, again hinting at potential disruption if this one day is no longer possible:

"...hair all nice and make up on, smart and a bubbly personality...I portray this sort of image."

Linda's story seems to be one of partial transformation, whereby she recognises some changes to how she experiences life as a result of cancer. However, her use of the analogy of a jigsaw puzzle, along with the emphasis she places on a desire to retain as much normality as possible suggests a partial avoidance of change. The overall implication might suggest Linda seeing illness as a challenge, a meaning category described by Luker et al (1996) as being related to a positive attitude and not dwelling on the potential impact of cancer:

"We don't let cancer rule our life, we control it...We dictate it and say right this is what we're doing."

This sense of standing strong in the face of adversity in order to make meaning from her cancer experience is balanced alongside such changes as a greater appreciation of life and a
greater respect for her body. This relates back to the beginning of this interpretation, as I reflected upon Linda's quest for a restitution narrative in the context of the changes that have taken place within her. Perhaps the phrase 'not giving in' and the meaning this has to Linda bears some relation to how she balances the two contrasting narratives. Frankl (1974: cited by Jensen et al, 2000) describes a pattern whereby some people react to suffering by mobilising an inner power or strength, which is perhaps what Linda is portraying in the following:

"Something just happens and I overcome it...something kicks in and I think to myself, right deal with it."

For Linda, the meaning of 'not giving in' may be represented by the strength she finds to deal with each diagnosis. Whether she is fully accepting the potential challenges of suffering is something we cannot determine. However, despite there being certain discrepancies within Linda's story, overall her goal appears to be to employ strategies that allow her to live a valuable life, and for her, this is conceivably how she gains meaning from her experience of cancer.

5.2.4 Analysing Judy

From the perspective of an ontological health model, there are three dimensions; it is the dimension of 'health as having/doing', whereby the person is focused on health problems and external matters of health behaviour, disease, and medicine (Arman & Rehnsfeldt, 2003) that Judy's story seems to begin. Her narrative focuses predominantly on the specifics of diagnosis, treatment and results, as opposed to the impact the overall experience has had on her sense of self:

"The worst thing for me about the chemo was that because it was a mixed one, I decided to use a cold cap in an attempt to stop my hair falling out. But despite going through the process of wearing it, my hair still fell out."

When I engage with Judy's story, the first thing that reveals itself to me is the body's war against itself, with the above recounting Judy's attempts to keep her hair by using a cold cap, but her body is working against her attempts. This suggests a self dissociated from her body, again shown in the below statement:

"They couldn't find veins; I had canula's in my groin, my neck, all over the place. Even my foot..."

With this "nightmare" occurring in her life, Judy strives for normality:
"I mean I'll never be 100% well. Well means to me a reasonably normal life."

The focus Judy has on being "well" offers an interesting dynamic to her story. I wonder if, amongst the story of physical trauma on the body, there is little space to renegotiate her sense of self to incorporate her breast cancer experience. Perhaps she has yet to give her body a voice to express this trauma, and therefore there is a potential risk of being silenced by the experience of cancer. Consequently, she turns to words such as "well" and "normal", perhaps as a way of reflecting upon how she would like to be.

When symptoms occur again, following primary breast cancer, the battle with her body commences. However, there is no opportunity to reclaim any sense of control over the body, as she reflects upon being inhibited by medical professionals:

"The doctor said, well you need to be able to walk out of here. And I responded, how can I walk anywhere? I was chained to the bed literally."

Judy seems to express a sense of being stripped of even a basic freedom of being able to walk out of the hospital. The description of being "chained" creates a strong image of Judy being imprisoned: imprisoned in her body, and also within the walls of the hospital.

Following her cancer diagnosis, Judy speaks of having an outer body experience. For Judy, at that point in her story, perhaps the only way in which she can survive this trauma is by separating her mind from her body. Such dissociation is generally thought to be a mechanism that creates a split in conscious awareness that allows the traumatised person to disconnect from parts of their experience in order to reduce the impact (Whitfield, 1995; Etherington, 2003). Moreover, Etherington (2003) describes phrases such as 'leaving my body' to describe how people refer to this dissociation, which fits with Judy's description:

"I felt like I had an outer body experience looking down on myself. It's like I didn't believe it was happening to me because it was just so surreal."

A dissociated person may also recall the trauma factually and in detail, with fewer emotional descriptions (Etherington, 2003), again fitting with Judy's narrative that has limited reflections regarding the impact on her sense of self and her related emotions. The yoyo image she offers of "feeling of going from down there, to up there" again suggests to me a disruption of control and stability.

Taking this disruption and trauma into account, one might ask what impact this has on Judy's identification of herself within society. In relation to Parson's 'sick role' (1951a, 1951b), for example, Judy does not fit neatly, as Parson assumes a relatively short-term,
temporary experience (Crossley, 1998). However, as she recounts her overall experience, it appears evident that the concept of the sick role encompasses Judy's experience of illness as incorporating certain institutionalised expectations:

"My current oncologist said that now I am under his care, he will keep hold of me and keep a close eye on me."

This statement suggests Judy has perhaps adapted to her situation by becoming dependent on her oncologist as a care-giver, expressing reliance upon doctors for knowledge. This power however seems at times to be a negative experience, with descriptions of being chained to her bed implying a situation controlled by the institutions of medicine and hospitalisation. Some criticise Parson's model failure to take sufficient account of the patient's agency and independence (Parsons, 1975, cited by Crossley, 1998), from Judy's narrative account, at times it seems that such agency is in fact difficult to maintain.

A feature of Parson's sick role is that it is undesirable and therefore temporary (Crossley, 1998). Taking this into account, one must ask, what happens when a person experiences ongoing, reoccurring illness, as is the case for Judy. The way in which Judy speaks of aiming for normality and going back to work suggests that, even if she had once taken on the sick role, she hopes to relinquish it for something more active:

"I got very reliant on the steroids, so my main thing is to try to reduce that reliance...So my main aim is to start moving again and get my weight down...I'm hoping that this Avastin will kick start me now, because I really want to get back to work."

Narrative psychologists discuss the concept of 'order of meaning', a concept that sees the human realm of meaning as related to 'activity', as made up of 'time' and 'sequence' (Polkinghorn, 1988: 4). Hence, experience is made meaningful, and understood in relation to this primary dimension of 'activity'. Moreover, Crossley (2000a) posits that a person experiences their sense of self in terms of a connection between time and identity. This can be seen in Judy's apparent introduction of 'therapeutic emplotment', a concept developed by Del Vecchio Good et al (1994), and used by Crossley (2003) to highlight the way in which patients may implicitly incorporate an underlying plot structure to their story. Although Judy's story is predominantly made up of recollections of the disturbance and disruption of her sense of time and sequence, the apparent plot structure she introduces implies a drive within her to instil meaning in the context of arduous treatment for breast cancer. This drive is perhaps expressed by an underlying temporal structure to her narrative, bringing
meaning to her experience. As shown in the above quote, Judy focuses on the immediacy of altering her medication and reducing her reliance on steroids, using the phrases "my main aim" and "my main thing" which may represent a focus following the chaos of the first part of her story.

In Judy's attempt to introduce a plot structure, there appears still to be a struggle with maintaining coherence, with what may be viewed as a struggle to make meaning of her experience in relation to interconnections between self and the world. In other words, despite what could be perceived as intentions for 'therapeutic emplotment', this appears fragile, as her cancer experience threatens to leave her with a meaningless story. Frank (1995) uses the metaphor of 'narrative wreckage' to characterise such an experience, and can be shown in the way in which Judy engages with her narrative of plans to go back to work:

"It'll be phased hours, until I get back to normal strength, doing what I normally do. I hope it doesn't take that long but we'll just have to see. I mean I don't want to put too much pressure on myself though...It's just one step forward, two steps back."

As discussed, Judy perhaps attempts to create and negotiate a plot structure "which places particular therapeutic actions within a larger therapeutic story" (Del Vecchio Good et al., 1994: 855). However, this seems to be a tentative attempt; her observation of taking "one step forward, two steps back" may express an underlying recognition of losing the battle. Judy's prognosis for the future is shrouded in uncertainty, as reflected by the way in which she questions which secondary cancer will ultimately kill her:

"I have got secondary cancer in my lungs, my liver, my bones and my brain...and any one of those will kill me."

Taking these future uncertainties into account, I wonder how Judy might make meaning from her breast cancer experience. When reading her story, I am struck by the fact that the sole input is from medical staff, with minimal room for reflection or insight from other 'insiders' who have experienced the same as she. Her only option when attempting to search for hope or meaning is to again listen to the medical staffs recommendations:

"...my doctor has said don't go back until you are ready."

Moreover, medication still appears to remain a controlling force behind the quest for normality. She speaks of her desire to come off the steroids, but this reliance will only be
replaced by another form of medication (Avastin). Judy's minimal narration of who she was prior to cancer, discussing only very briefly her role as a legal secretary, seems to reflect a struggle to recount her identity prior to being sick. Judy has been let down by her body, and is therefore left in an ongoing crisis of control, with no secure sense of self. Frank speaks of 'body-relatedness' with the question "do I have a body, or am I a body?" (1995: 33), referring to the extent to which bodies are associated with or dissociated with (although he does note that this is not a linear process). Even the most basic process of eating seems to leave Judy with a sense of dissociation from her body:

"I have never, ever been this heavy in my life. I was ninety-five which really was my heaviest. And I've just gone up to ninety-seven. I can't understand it because I'm hardly eating anything."

Frank (1995) notes that as long as the body is healthy, with mortality not at the forefront of one's thought, associating the self with the body comes easily. However, when, like Judy, there is recognition of mortality, along with an awareness of the troubles that the body can encounter, body dissociation can occur. Therefore, perhaps in Judy's case, there is a struggle to make meaning or commit fully to future plans, as she is a self without a reliable body. I wonder if, in order to make meaning from this experience, space to reflect upon the body-self connection would be necessary.

Despite this body-self disconnect, there is, contrastingly, a pleasure in connecting with the earth and nature:

"Everything has been heightened emotionally. You also appreciate animals and nature more."

This transformation and increased appreciating of nature, suggests potential for a phenomenon referred to by Chiu (2000) as 'letting go of grasping', whereby women describe an openness to the universal. Whilst Judy's story does lack the often reported transforming processes and discovery of meanings in relation to her sense of self (see Arman & Rehnsfeldt, 2003), the subtle alterations in her awareness perhaps hints at the beginning of a process of transformation. Referring back to the initial ontological dimension of 'health as having/doing' (ibid) as a way of understanding Judy's focus on external matters of disease and health problems, if we look at her narrative as a whole, there are suggestions that as her cancer journey develops, she is able to move towards a different ontological level that incorporates her deeper needs to be grounded through nature. In the dimension of 'health as being', Arman and Rehnsfeldt (2003) discuss an
experience whereby "values and awareness of life are altered, an expanded consciousness and openness often creates an appreciation of life for women stricken with breast cancer." (p.521). Therefore, perhaps it is through this that Judy can begin to make meaning from the chaotic experience of breast cancer and ongoing medical treatment.

5.3 Reading across stories

It has been my intention to use the above analyses of four individual stories to illustrate marked variations in individual's interpretations and meanings made from the experience of breast cancer. Whilst each case is unique, there are certain connections that appear to occur across the stories. As noted in Chapter 3, Riessman (2008) states that the analysis of individual cases in their own right can be combined with category-centred modes of analysis. Although narrative analysis is case-centred, it can generate concepts that "prompts the reader to think beyond the surface of a text, and...move toward a broader commentary" (Riessman, 2008: 13). This section of Chapter 5 therefore considers the insights I gained when reading all four stories. The links I draw upon may not have been noticed in one story had I not read a previous story, thus highlighting the importance of a reading across stories.

5.3.1 The use of metaphors

Lakoff and Johnson (1980) describe the essence of metaphor as understanding and experiencing one kind of thing in terms of another. As a vehicle for understanding and mediating what is known and what is unknown, therefore, metaphors can be a powerful tool for health care professionals in the field of psycho-oncology to use in order to help patients understand illness:

"...for patients, metaphors can impose order on a suddenly disordered world, helping them to understand, communicate, and thus symbolically control their illness" (Reisfield & Wilson, 2004: 4024).

I will now move on to discuss the metaphors that naturally emerged from the narratives of each woman.

Reisfield and Wilson (2004) discuss the 'martial metaphor', whereby cancer is seen as the enemy for the patient to combat. The combative language of fighting and beating cancer has the potential to counteract the powerlessness and passivity often associated with illness (Hawkins 1999: cited by Reisfield & Wilson, 2004). This can be seen in Rosemary's comment about her cancer:
"I regard cancer as some sort of alien...it's intruded on everything...it's this thing you've got to beat."

This metaphor of war she uses is in fact based on experiences that occurred in her life away from cancer, as seen by her reference to catching and fighting robbers ("I've caught a lot of robbers"), and compares this experience with that of breast cancer:

"And it's the same with cancer, it's this thing you've got to beat, and it's no right to be there."

Similarly, Linda comes to think of her cancer as something to dictate:

"We don't let cancer rule our lives...We dictate it."

Our knowledge of dictators is likely to create an image of one who has obtained control by force, with attempts to dictate being linked to a power struggle. Whilst this war and dictatorship metaphor clearly resonates with both Linda and Rosemary, it does have some limitations, as evident in the other narratives. Connotations of war are naturally masculine and power based (Mitchell et al, 2003), with language that suggests winning the war, or defeating cancer, is simply a matter of fighting hard enough. Concern around this arises from the fact that there are no actual enemy invaders: the enemy is the self (Reisfield & Wilson, 2004). It is in this way that Caroline engages with the war metaphor:

"You're a ticking time bomb from now on really."

Her words imply a war whereby the enemy is the person, which could explode at any time, causing more destruction, hinting a lack of control within this fight. A further concern with the metaphor of war is its association with identity traits of bravery, the very trait that Judy rejects:

"I don't see myself as brave, I just see myself as someone who has to go through it. I have no choice."

Whereas Linda's words suggest an empowering stance of dictatorship, Judy's narrative does not convey the same experience. In contrast, Judy introduces a metaphor of imprisonment, and a losing battle, with the image of being "chained to the bed". The metaphor of being a prisoner again is implicated when she speaks of being "under his care, he will keep hold of me and keep a close eye on me", when she refers to her oncologist. In the context of a war metaphor, Judy appears as a prisoner of war: a prisoner in her own
body, with her consultants acting as the prison guards, and controllers of her life. Judy describes an experience as if being attacked:

"I had canulas in my groin, in my neck, all over the place...I felt like they were hacking me to death."

In contrast to other narratives, Judy's narrative does not meet this attack with a fight back, therefore warning against generalisation of specific metaphors.

A further way that the women in this study conceptualised their breast cancer experiences was through the journey metaphor; one which is particularly applicable to cancer in the 21st century, as for more people it is a chronic illness, enmeshed in the lives and stories of those with a diagnosis (Reisfield & Wilson, 2004). The metaphorical mapping of life as a journey in which cancer is an obstacle (Gibbs & Franks, 2009) is one way of conceptualising the experience of cancer. Caroline, for example, engages with the journey metaphor when that "life really is on hold", hoping to "get the green light at the end of treatment". Reisfield and Wilson (2004) posit that patients devise metaphors based on things they know and value, which appears to fit with Caroline's processing of her illness experience. One might assume that Caroline, before cancer, lived life as a fast journey, as shown by the way in which she comments "I used to be able to get up at 4 o'clock in the morning, get on a flight and come back the same day." Interestingly, Caroline uses the term "condition" to refer to her breast cancer. The Oxford Modern English Dictionary online defines condition as 'something affecting the functioning or existence of something', fitting again with the way in which Caroline applies the journey metaphor to her experience of breast cancer. Caroline appears to be making meaning of her breast cancer experience in terms of a halted journey, whereby her functioning along this journey has been affected by her current condition. Gibbs and Franks (2009) explain this meaning-making process as seeing cancer as 'an obstacle on life's journey' based on a higher level mapping of life as a journey. If a person relates to the concept of travelling through life, and navigating oneself towards goals and values, perhaps the journey metaphor is likely to be a pervasive one.

A further interesting interpretation of the journey metaphor is one whereby journeys taken in life can be related to the discourse used to describe the cancer journey itself. For example, Rosemary at first introduces the discourse of a journey metaphor in a way not directly related to cancer:
"I continue to do things like walking...I love driving. I love going places in the car, drive for miles and then come back. When I'm in the car, I know I'm in control"

Although she discusses travel in terms of getting in her car and feeling in control, it is interesting that travel is something she introduces spontaneously into her breast cancer story. In contrast to the feelings of control she experiences when taking a journey in her car, Rosemary reflects on times throughout her cancer journey when she has felt "carried along". In this respect, Rosemary has been thrown out of the driving seat, with the image of being carried along implying a loss of agency with regards to goals, direction, and progress; terms often associated with being on a journey (Reisfield & Wilson, 2004). A journey of struggle is also echoed in Judy's reflection of going "one step forward, two steps back." Her words fit with a metaphor of a journey, in which she is going backward, suggesting chaotic and disrupted travel.

The concept of cancer challenging the original path being travelled is a further aspect of the complex journey metaphor. As stated by Linda:

"I used to party a lot. I worked in London, so when we'd complete a deal we used to party all night after work and go home to bed for a couple of hours and then get back up and get on the train back to London again."

This commentary conjures up a life of living in the fast lane. However, Linda's enduring breast cancer experience changes the direction of her life toward a different path:

"Those days are long gone...I do look after my body a lot more now, and respect it a lot more...this experience makes you wake up and see life for what it is."

For Linda, cancer appears to have cleaned her life path and allowed her to attend to her life with more value. For Linda this changing life path is expressed as a positive one, but it can also lead to disruption, as seen in Caroline's narrative:

"My whole world was turned upside down. It wasn't just about having to come to terms with the disease, everything stopped, and everything changed, overnight."

This challenge appears to bring about feelings of disorientation and questioning of what the new journey will look like.

All four women used multiple metaphors, supporting the findings of Gibbs and Frank (2009). For instance, Linda also used the metaphor of cancer as a puzzle, in conjunction with the journey metaphor and war metaphor:
"I see the experience as being like a jigsaw puzzle in a way, with all the pieces fitting together so we get the outcome which is remission...you go so many steps forward and then back again".

Along with conceptualising her experience of breast cancer with a journey metaphor, Linda extends this metaphor to include a puzzle. Both metaphors have different meanings and are likely to serve different purposes in how makes meaning of her experience. Whilst the journey metaphor offers Linda language fitting with the progressions she at times makes, the jigsaw puzzle metaphor conceptualises cancer as a game. Similarly, Lakoff and Johnson (1980) conceptualise the metaphor "life is a game" as people taking chances and playing their cards right. Moreover, there is an understanding that we are dealt a hand of cards that are beyond our control, but we are responsible for what we do with these circumstances (Gibbs & Franks, 2009).

Further analysis of the metaphor of cancer as a puzzle could also be interpreted as implying a solution and an end result. Frank notes that "modernity seeks to turn mysteries into puzzles" (1995: 81), and the image of a puzzle assumes something that can be solved. In Linda's case, perhaps the restoration of normality is her hoped for prize if she solves the jigsaw puzzle:

"I want normal, I want as much normality as possible."

Whilst this metaphor may, in a similar way to a war metaphor, encourage a focused and motivated stance, its limitation is the lack of space for accepting that at times cancer does not have a solution, and people do not restore themselves back to normality.

By paying attention to the stories of these women, the potentially pervasive nature of metaphors in the thoughts and speech of some breast cancer patients has been highlighted. The four women in this study used multiple, and sometimes contradictory metaphors to conceptualise their complex cancer experiences and describe the meaning they make from such experiences. These contradictions indicate the diversity of thoughts and emotions that women have when they experience breast cancer, and engage with diagnosis and treatment. Although none of the women in this study spoke explicitly about their use of metaphors, it is evident that metaphor played an important part in the construction of meaning, offering an understanding separate to empirical and logical knowledge (Lyddon, Clay & Sparks, 2001).
5.4 Conclusion

According to McAdams, "good stories give birth to many different meanings, generating children of meaning in their own image" (1993: 30). It is from this that I conclude that the meanings presented, both in the context of the single-case interpretations and also the cross case interpretations, are only one partial set of meanings, shaped by my own experiences and understandings of the context of breast cancer. If read and interpreted by another, new meanings are likely to resonate (Etherington, 2004). However, this in itself is part of the value of researching with stories, as they give us different ideas and opinions, therefore avoiding attempts to understand individual experience from the perspective of theoretical constructs that do not encourage diverging views. As I immerse myself in the stories by listening to, writing down, and reading through them, I began to make sense of my own experiences as a counselling psychologist, and of the women's experiences as storytellers (Frank, 1995). In Chapter 7, I relate the meanings and interpretations discussed above to the field of counselling psychology. First however, I will pause to reflect upon my own story, and the journey I have taken throughout the research process. As with the women in this study, I too have formed a story, creating a coherent ordering of experiences. In Chapter 6, I will endeavour to tell this story.
Chapter 6

Reflexive Analysis

Organisation of Chapter 6

Introduction
Disciplinary reflexivity
Personal reflexivity
Research as a vehicle for change and development
Conclusion

6.1 Introduction

The dominant methodological approach to psycho-oncology research has involved the use of quantitative methods. In this chapter I will reflect upon my choice of qualitative methodology, as outlined in Chapter 3. Whilst the traditional positivist approach to psychological research treats the researcher as emotionally distanced and unbiased beings studying human behaviour (Griffin & Phoenix, 1994), other researchers, including those coming from a feminist perspective, have argued that research is never value-free and unbiased. Griffin and Phoenix (1994) consider such positivist research as having the potential to be counterproductive to the potential development of one's field and theoretical preferences, and instead suggests the need to focus also on making transparent the contexts in which the researcher and the researched live their lives. It is from this that the concept of reflexivity is borne; a concept referred to by Wilkinson (1988) as a disciplined self-reflection. Leading on from Chapter 1, whereby I explained the genesis of the study through a personal, practical and social justification (see Clandinin & Huber, 2010), I will endeavour to make transparent my own theoretical and philosophical standpoint, as a counselling psychologist, as someone choosing to research in the field of psycho-oncology, and as a woman carrying out research with other women. Moreover, I will aim to explore areas of the research process that I feel are of relevance to the exploration of researcher-involvement throughout the present study.

Beginning with a reflection upon myself as a practitioner, and the process of development from practitioner to researcher, I discuss the impact of the philosophical stance of my training on my approach to research. I will then turn my reflexive awareness to the influence of the oncology placement I undertook on my interactions with the participants throughout the research. This will be understood in terms of three types of reflexivity:
'personal' and/or 'functional' reflexivity raise issues relating to the identity of the researcher and the form of the research, whilst 'disciplinary' reflexivity entails analysis of the nature and influence of the field of enquiry (Wilkinson, 1988). In each case, reflexivity can be understood as "the capacity of the researcher to acknowledge how their experiences and contexts...inform the process and outcomes of inquiry" (Etherington, 2004: 32). The reflexive analysis in this chapter represents a bridge between research and practice (Etherington, 2004), and I will therefore end the chapter with a consideration of personal developments that might have occurred within me throughout my research journey.

6.2 Disciplinary reflexivity

'Disciplinary' reflexivity (Wilkinson, 1988), is the requirement for a discipline to explain its own form and influence, with literature documenting how the disciplinary background of a researcher affects what they choose to study, how they proceed, and what they find (e.g. Kahn, 1972). Fitting with the social constructionist philosophy of this study, such reflexivity is important in that it accounts for the existence of multiple realities that inform one's research. As discussed in Chapters 2 and 3, I embarked upon this study from a philosophy that embraces the subjectivity of human experience. Although coming from a psychology background, whereby the dominant paradigm is one of positivism and empiricism, this is not the paradigm under which I operate as an individual and as a practitioner. I specifically chose the field of counselling psychology as I felt it would also offer me an opportunity to develop personally, not just professionally. This can be seen from an excerpt written in my reflexive journal, written in the first week of first year:

"I realised more and more through the first week that when I look at my motivation to start this course, it is based as much on personal development and self-awareness as the professional development and knowledge that I hoped I would also gain.

The reason I comment on this is because my decision to pay attention to what sometimes becomes a neglected self also influenced the focus of my research on meaning-making and transformations. Reflecting on my journey into the course, through my training as a practitioner, and then moving from practitioner to researcher, it is evident that my own need for transformation led me along the path towards my chosen research.

6.2.1 How we hear stories

As I contemplate my own story about becoming a reflexive researcher, I feel it is important to examine how I arrived at the decisions I made in the process of research, and the
influence of the discipline from which I develop my identity as a researcher. The doctoral training I have embarked upon for the past two and a half years embraces a pluralistic philosophy, as captured by the following quote: "The doctrine that any substantial question admits to a variety of plausible but mutually conflicting responses" (Rescher, 1993: 79). It is a philosophical standpoint that fits with the field of counselling psychology, in that it emphasises respect of contrasting responses and worldviews, placing particular emphasis on the experience of clients, and the stories that clients tell about what their current distress means to them. This philosophy undoubtedly influenced the way in which I carried out research, and encountered the women in this study.

With hearing the stories of clients being at the centre of the therapeutic endeavour, I sought a research approach fitting with this, and the underlying values I hold. Returning once again to the pluralistic framework, a collaborative relationship between the therapist and client is valued; placing the client's views at the centre of importance (Cooper & McLeod, 2007). From this perspective, when reflecting upon what I hoped to achieve from this study, my aim was to replicate the collaborative stance, valuing the participant's view, rather than imposing preconceived questions coming from the agenda of the researcher. However, due to the collaborative nature of therapy to which I am accustomed, perhaps the stories carry more of my participation than if I had come from a different profession. When I read and re-read the transcripts, one point that stands out in my reflexive journal is the way in which I note the nature of the transcripts:

"This was the first time I had ever carried out qualitative research, and I was struck by the fact that the narrative encounters felt remarkably like therapy. When I met Linda for example, I asked how the experience had been for her. She said she felt it might have helped a bit. This made me wonder about the links between therapy and research."

Some counselling literature in fact recognises the therapeutic value of research, and the benefits that may come from blurring the boundaries between research interviews and therapy (see Etherington, 2001). Interestingly, however, towards the end of my encounter with Judy, she reflected on the difference she had experienced between previous counselling and the telling of her story in this study:

**Excerpt 6.1**

<table>
<thead>
<tr>
<th>Extract from the Transcription of Judy's Narrative</th>
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<tbody>
<tr>
<td>EC: So how's it been talking about everything with me today?</td>
</tr>
<tr>
<td>JE: It's been fine. It was good talking, I enjoyed it. It puts everything in perspective in your mind.</td>
</tr>
</tbody>
</table>
Erm, and it's funny because erm I don't normally like talking about personal things with strangers.

EC: mm.

JE: Erm, my brother died erm...twelve years ago and my doctors sent me to...to see somebody about it because I was in a bit of a state. So I went to see this counsellor. And I just hated it.

EC: Really?

JE: Hated it.

EC: What was it that you hated?

JE: I didn't think I was getting anything out of it. You know....I was talking but....I don't know, she said do you want to come back, and I said no.

Despite my own reflections of the similarities between research and therapy, clearly Judy feels differently. Although it may have been interesting to take this discussion further, Judy quickly progressed on to a different topic, and I sensed it would have been my own agenda if I had moved the conversation back to therapy versus research.

6.2.2 How we analyse the stories

Due to the nature of our training, for many counsellors and psychotherapists gathering stories is achieved with ease; problems may arise when we reach the stage of determining how to make sense of and represent the stories that we have gathered (Etherington, 2004). Again, relating back to the philosophy I take as a counselling psychologist, my focus is individual subjective experiences. Consequently, when approaching research analysis, my intention is to place each woman at the centre of the inquiry, rather than as subjects of research. Accordingly, I chose firstly to present each story within the thesis in its own right as a restored prose version of the original transcript. I then hoped to interpret each story as if I was retelling the story, rather than searching for conceptual themes. During the analysis I recalled an excerpt from my reflexive journal that I had written throughout my oncology placement:

"I feel like everyone has to learn to deal with cancer in their own individual way, and so therapy seems to be about helping my clients through the messiness and chaos, in order to find their unique path."

If each path is unique, then it seemed to make sense to represent each story in a way that values the depth and texture of each woman's unique experience. As written by Yalom, "to become wise you must learn to listen to the wild dogs barking in your cellar" (2008: 206), a statement which for me summarises my therapeutic experience in an oncology setting,
emphasising the importance of embracing an exploration of fears and existential issues. It is my belief that this can only be achieved if we cast aside rigid frameworks and techniques. Whilst this belief is based on my therapeutic experience, I have attempted to relate it to my research approach. I hope making my philosophy as a practitioner transparent reveals to the reader the impact of my therapeutic work on the process of my research.

My intention in this section was to express how the discipline of counselling psychology has impacted how I listened to the stories and then how I represented the voices of the women in my study. However, this is only part of the story of reflexivity. My own life story and identity outside of my profession is another aspect that constructs the process in which I carry out research. It is this that I will now endeavour to articulate below.

6.3 Personal reflexivity

In her 1988 paper, Sue Wilkinson considered 'personal' and 'functional' reflexivity, as being inseparably linked, relating to the identity of the researcher and the form/function of the research: for me, I am a woman of a certain age, training to be a counselling psychologist. Whilst features of my personal identity are likely to have an impact upon the research, the topics one chooses to study in the first place are likely to derive from personal concerns. In the case of this study, research focuses on the transformations that take place in women who have had breast cancer – although I have never had cancer, I am a woman and I have an interest in how people transform from the suffering that life can bring. In fact, an essential part of a feminist research paradigm is the emphasis of the centrality of personal experience on the research we carry out and how we interact with it (Callaway 1981: cited by Wilkinson, 1988).

As I reflect upon how my own identity and life experiences lead me to becoming a reflexive researcher with an interest in identity transformations, I began to look back through my reflexive journal spanning over the whole course. This allowed me to focus on myself separate to my identity as a trainee counselling psychologist. The diary excerpt below introduces how my life experiences inspired my initial therapeutic work in an oncology setting:

"I went for an interview today for a placement at a cancer hospital. The interview really offered me a reminder of the influence my close friend's breast cancer diagnosis has on how I live my life day to day, and the opportunities I choose to embrace. The transformations that I saw her make to her life left a positive impact
on me; I noticed most clearly in the interview today almost a need to engage in conversations that confront the things that most people tend to avoid: mortality and suffering, but then also the potential changes that can take place if we face up to these realities.”

This excerpt from my reflexive journal not only highlights to me why I have been drawn to the writings of Irvin Yalom throughout my practitioner training, but also why, from the first year of training, I immersed myself in learning about the experience of illness and the meanings that people make from such experiences.

To summarise my reflections so far, in true narrative structure, I have acknowledged my present identity, both as a researcher and a practitioner, in terms of a remembered past. A further aspect of ‘personal’ reflexivity relates to my identity as a woman. In feminist research, focus has been placed on the importance of women interviewing women, as a consequence of the gender-based power differentials traditionally existing in interview situations (Griffin & Phoenix, 1994). Although it is not possible to deduce whether the fact that I am a woman produced richer or more in-depth data, I do recall female clients with breast cancer reflecting upon feeling more comfortable opening up to a female therapist. Therefore, I wondered at times during the encounters whether having a female researcher helped the participants express their stories more freely. For instance, during my encounter with Caroline, she informed me of the lack of intimacy she was experiencing:

**Excerpt 6.2**

<table>
<thead>
<tr>
<th>Extract from the Transcription of Caroline's Narrative</th>
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<tbody>
<tr>
<td>CW:...and my husband's not very touchy-feely at all. I am. Very...like lots of cuddles and hugs and things like that. A lot of reassurances....</td>
</tr>
</tbody>
</table>

This is just one example of the openness that I experienced in the narrative encounters with the four women. However, this does not indicate that this would not have been to a male interviewee, and I wonder if this perhaps is an area that could have been useful for me to inquire into if an appropriate moment in the encounter had arisen.

In reaction to masculine assumptions of quantitative psychological research, feminists have tended to stress the value of qualitative methods whereby research begins from women's experiences (Wilkinson, 1986; Kasper, 1994). Historically, dominant assumptions have
been that, following a lumpectomy or mastectomy, the main cause of anxieties for women are based on changes in appearance (e.g. Derogatis, 1980; Holland & Mastrovito, 1980). I was sensitive to the fact that such assumptions may not be appropriate for many, and it is from this that I attempted to interpret the stories in Chapter 5. Throughout each narrative encounter I maintained an internal dialogue, ensuring that I did not introduce any topics that came from my own preconceptions. My hope was to collaboratively produce unique stories with each woman (through the initial storytelling process, and then process of restorying which I shared with each woman) and then interpret the stories in a way which I hoped would fulfil feminist objectives of being fully representative of the women's own stories. Whether this is something that was easier for me to achieve as a woman encountering other women is something that would require further enquiry.

In the positivist research paradigm, the relationship between the researcher and the researched is an impersonal one: the researcher predicts and controls the researched (Wilkinson, 1988). By introducing reflexivity into account, the psychological processes between the researcher and the researched is acknowledged, along with the impact of my own identity and the participant's interpretation of me. Interestingly, all four women asked me about my role at the hospital, and I therefore felt it important to share with them the fact that I had worked for a year there as a trainee counselling psychologist offering therapy to patients. Although the impact this might have had on the stories they told me will remain unanswered, a constant scrutiny of the way I was interacting with each lady was important. Rather than to ignore the power that my position within the research relationship held, I took a stance of acceptance and monitoring (Etherington, 2004). I feel my attitude to the relationship with my participants and the potential impact of my own personal identity is reflected in Ruthellen Josselson's words:

"I would worry most if I stopped worrying...To be uncomfortable with this work, I think, protects us from going too far. It is with our anxiety, dread, guilt, and shame that we honour our participants...We must at least try to be as aware as possible of what we are doing." (1996: 70).

6.4 Research as a vehicle for change and development

The influence of the context from which a researcher comes is only part of the story; the second part to reflexive analysis is asking how research feeds back into life experiences (Wilkinson, 1988). As a full-time doctoral student, I realised I needed to choose a topic of inquiry that would sustain my interest and energy over a prolonged period. I hope from the above reflections, I have expressed the reasons for my topic of enquiry. From this initial
interest, and throughout the process of research, the way we as researchers attend to our life experiences may transform and grow. I reflect back to the recruitment stage of my research, when I had to speak with a medical consultant in order to gain his permission for me to interview his patients. I was met with a lack of encouragement, in particular due to the fact that I was intending to use an unstructured interview. The consultant informed me of his belief that the interviews would be very short and I would not get anything original from the women that I met. I experienced feelings of insecurity and self-doubt, as seen by the following reflection from my journal:

"Being new to research, the consultant's reaction has made me wonder whether I should be using a more structured approach to the narrative interviews. It's reminded me of feelings I have experienced before of not belonging to the world of research. As a practitioner, I have comfortably let go of the need for certainty, often trusting my intuition instead of structured protocol. My approach to research seems to reflect my comfort in embracing uncertainty; but I wonder if my inexperience means I should have chosen a more traditional and safer way to research."

Despite discussing this with my peers and supervisor, a certain amount of doubt still existed when I met the first woman. In hindsight, I feel as though my research experience has encouraged me as a practitioner to continue to embrace the messiness of human existence rather than attempt to compartmentalise it into something neater. Cognitive-Behavioural Therapy (CBT) is increasingly promoted as the treatment of choice in the UK (Merret & Easton, 2008), and I would compare the pressure I felt to alter my research to fit in a structured interview schedule with the pressure I also experience as a practitioner to explain my therapeutic work in terms of generic formulations and scientific, rational methods that are favoured in CBT. Through supervision, personal therapy, and reflexivity, I have become comfortable with a practitioner identity that regards therapy as a mutual struggle between therapist and client. This point is summarised by Starhawk's reflections of the therapeutic process: "Healing that empowers and liberates springs from a mutual struggle with the forces that hurt us all" (1987: 147). My reflections from this study have not only cemented my faith in trusting in the uncertainty that plays a large part in much of the therapeutic process, but has also allowed me to trust in 'letting go' of certainty throughout the research process.

This personal development came about as I encountered each woman in a research setting; I was simply there to hear a story. By removing the pressures that I sometimes feel to
fulfil the needs of a client, I was able to open up and listen to the stories without
distraction. This is expressed in the following excerpt from my reflexive journal, as I
reflect upon how the narrative encounters have changed me as a practitioner:

"I think in some ways it has changed my practice. It has allowed me to take a step
back and keep in tune with what the client is really saying, rather than jumping
ahead to what I should be doing to make the situation better for the client. It has
made me more open to going with the flow of the client and having faith in this
process."

One particular example that allowed me to make such reflections occurred during my
encounter with Caroline. Not long into her story, the below interaction took place:

**Excerpt 6.3**

<table>
<thead>
<tr>
<th>Extract from the Transcription of Caroline's Narrative</th>
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<tbody>
<tr>
<td>CW: Yep. So, erm.....yep......Have you got another question?</td>
</tr>
</tbody>
</table>
| EC: No, I mean I was kind of opening it to how you feel - I mean, I wonder how it's been for you
talking about it like this? |

One response to Caroline's question (and it did cross my mind momentarily) would have
been to worry that I did not have a pre-planned set of questions that I could then consult.
However, as I would in a therapeutic setting, I focused on the process of the interview.
Yalom (2002) speaks of the difference between 'content' and 'process', two major aspects
of therapy discourse. Whilst 'content' refers to the words and issues being addressed,'process' refers to the interpersonal relationship between the parties engaged in an
interaction. Excerpt 6.3 offers an instance in which I hoped to explore the nature of the
interaction between Caroline and I, and how she had experienced the encounter so far.
Caroline went on to recount how she had attempted to share her cancer experience with
others; an aspect of her story which may have been lost, had I been relying on an interview
schedule.

In summary, the process of research I feel has allowed me to continue to develop my skills
as a practitioner. The approaches I took to the narrative encounter with each woman and to
presenting and interpreting the stories will inform how I work with clients in the future.
As I reflect upon the story of my research journey, and as I tell the story to other people, I
find myself looking at the narrative of my practitioner journey from a fresh perspective.
The positive experience of simply telling their story that was spontaneously expressed by
three of the four women I feel has given me permission to continue to develop my practitioner identity toward a therapy that embraces unique stories of the individuals we encounter, basing our therapeutic work on the realities of existence, not on the techniques that we can offer (Yalom, 2008).

6.5 Conclusion

Rhoda Unger (1983) clarifies the nature and function of the research enterprise by asking the following questions: how is the form of our research shaped by our values, life circumstances, role in society (as a woman), ideology (pluralistic and humanistic); and what part does the form of our research play in creating our concepts and hence constructing our knowledge? In this chapter I hope to have clarified how the answer to the above questions have impacted the way in which I carry out research, and the path I have taken in the process of research.

Having used reflexivity as an interesting sideways step to look at what was actually going on for me throughout the research process, I will now turn my focus once again to the stories. In Chapter 7, I will discuss how the interpretations of the stories I made in Chapter 5 might potentially impact the field of counselling psychology.
Chapter 7

Discussion: The Research Issues Revisited

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7.1 Introduction

The purpose of this study was to consider possible responses to the following questions, by reporting on four women's breast cancer stories:

What insights do women's narratives provide regarding how they make meaning from their experiences of breast cancer?

What implications might there be from such insights for counselling psychology?

In this chapter I will complement the expanded understanding gained from the study with a discussion relating to existing literature, and consider the insights gained through the analysis in Chapter 5. The interpretations discussed in Chapter 5 are intended to offer new insights and open up further paths of enquiry (McLeod, 2009).

The aim of this research was to explore understandings of the experience of breast cancer, and the meaning-making process that takes place through stories. The study design provided an opportunity to present the stories of four women who had experienced breast cancer, with inspiration coming from feminist research intentions to place women at the centre of the inquiry (Kasper, 1994). Each of the women provided a personal and detailed account of their experience through their narratives, therefore capturing these women's breast cancer experiences from the standpoint of their words. My intention was not to identify themes that arose across each story, but to offer interpretations of the stories as a whole (Connelly & Clandinin, 1990), taking into account existing literature. As stated by Sandelowski (1991), narrative analyses of texts force scholars to attend to what is placed immediately before them, before transforming them into descriptions of the lives they represent. Using a narrative approach offers an opportunity to gain insight into the way...
human beings understand and enact their lives through stories. Therefore, the hope of this study was to enrich what we already know, and perhaps gain further insight into the experience of breast cancer.

In the below section I will consider the differing ways in which the women engaged with their breast cancer stories, focusing on: i) the impact the experience had on their sense of self; ii) their discussions of changes in appearance, and how this fits with past research findings; and iii) the use of metaphor in the women's narratives. This chapter ends with a discussion related to the second research question:

*What implications might there be from such insights for counselling psychology?*

With this question in mind, I will consider how, as counselling psychologists, we could possibly meet the needs of women with breast cancer.

### 7.2 The issues arising from analysis

#### 7.2.1 Engagement with breast cancer; changing sense of self

*I won't kid you. There are two Lance Armstrong's, pre-cancer, and post. Everybody's favourite question is 'How did cancer change you?' The real question is how didn't it change me?* (Armstrong, 2000: 4).

Whilst insight into the experience of breast cancer have come from diverse studies, a qualitative metasynthesis by Arman and Rehnsfeldt (2003) showed that the experience of suffering, might have been overlooked in research that depicts breast cancer as a force involving transformation. Indeed, if we are to look at autobiographical narratives such as that of Lance Armstrong (2000), as quoted above, then the idea of quest and transformation is prolific (Frank, 1995). Armstrong suggests that identity change is inevitable, with research suggesting that traumatic life experiences destroy one's fundamental assumptions about his or her identity, and the way in which the world is perceived (Janoff-Bulman, 1992: cited by Janoff-Bulman, 2004). In this section I question how women engage with the concept of transformation and changing sense of self. Whilst my research did not explicitly question views of transformation, it did open up the possibility of hearing how women engaged with this concept.

For the women in this study, narratives implied varying interactions with their sense of self. In Rosemary's narrative, the impact of breast cancer on her identity appears initially minimal, with little focus on change and transformation; instead there is a striving for normality. As discussed in Chapter 5, such an engagement with cancer fits with a meaning
of seeing cancer as a challenge (see Lipowski, 1970), a narrative style reflecting Rosemary's apparent sense of agency over her breast cancer. Therefore, rather than transforming, her identity remains strong. Expressing strength in the face of adversity, is something that appears to come out of the narratives of Linda and Rosemary (also found to be the case by Luker et al, 1996), and perhaps can be understood in term the British culture of maintaining a 'stiff upper lip'. This sense of agency, however, is something which is contradictory in many of the narratives, having implications on the perceived sense of self. Even Rosemary herself hints at certain experiences of losing control and agency, whereby she recalls feeling as though she was being "carried along". Rather than a changing sense of self, another interpretation of this could be an involuntary struggle. For many of the women, in fact, there appears to be an oscillating process of engagement with their experience of breast cancer, which is highlighted here in Rosemary's narrative. On the one level, she engages with a narrative that resonates with the 'restitution' plotline, whereby a 'normal' trajectory remains intact (Frank, 1995). Within this narrative type, there appears to be little room for suffering or transformations. This is a narrative type that Linda too appears to strive for at times. However, for both Rosemary and Linda, if we look closely at their stories, change could be perceived as inevitable. In Rosemary's case, there appears to be a subtle recognition that cancer could alter her strong sense of agency. For Linda, there is a sense that her breast cancer experience has resulted in an increased awareness of life and a higher prioritisation of her own needs.

Of interest, although the restitution narrative is a difficult one to maintain, it nonetheless appears to be striven for by two of the women, as opposed to a narrative of transformation, with illness as impetus for change (Frank, 1995). Although Linda reflects on what could be perceived as positive changes, expressing the way that breast cancer "makes you wake up and see life for what it is", nonetheless, there seems to be initial resistance to acknowledge the changes:

"I want normal, I want as much normality as possible."

The impact of breast cancer on a person's sense of self and the desire to engage with potential transformations may be influenced by an individual's 'frame', as shaped by the historical context of their existence and the social circumstances of their lives (Doherty, 2011). So, Rosemary's narrative reflects a possible frame of someone who has "always worked long hours...so I never used to sit around thinking." Instead of reflecting on change and meaning, Rosemary approaches cancer from a practical frame of reference, seeing it as "this thing you've got to beat". In contrast, Caroline's frame is one of someone...
who is analytic, with a strong professional identity; therefore, cancer is something that challenges her prior identity, seeming to result in an incoherent narrative. As a result of this disruption, Caroline appears to engage in what has been referred to as 'biographical work' (Mathieson & Stam, 1995), whereby she makes decisions regarding how the events of illness fit within the context of her life:

"I wonder, do I want to be the person that I was before, or the person that I am now?"

Mathieson and Stam (1995) found that over time the cumulative effect of the change resulting from cancer leads to permanent transformations. For Caroline, perhaps there is nothing as yet to replace her old narrative and identity with, despite an engagement with possible transformative discourse. Linda however begins to note explicitly changes that have taken place as an effect of her breast cancer experience, thus fitting with this 'cumulative effect' (Mathieson & Stam, 1995); after over ten years of cancer treatment, Linda's narrative begins to accumulate and acknowledge transformations. Both of these women's narratives fit with a view of transformation that incorporates "the reworking of former experiences, as well as the complexity and the nonlinearity of the transforming phenomenon" (Arman & Rehnsfeldt, 2003). A possible rationalisation for the lesser engagement with transformation and change in Rosemary's narrative is based on findings from Kaiser (2008). She considered women's engagement with the survivorship identity, and found that women over the age of sixty-five relied on the discourse of an ageing body, and, therefore did not see survivorship as a salient part of their identity. Similarly perhaps for Rosemary, the discourse of an ageing body offers enough meaning to the experience of breast cancer. Conceivably, this may also reflect her ability to recognise that the meaning of cancer lies in its meaninglessness (Willig, 2009):

"I'm just another person, there's loads of people get it, so why am I different?"

Of note here, is the absence of Judy's narrative in this discussion about transformations, with her engagement with this phenomenon only coming right at the end of her story. This is perhaps the result of the physical suffering reflected in Judy's narrative recalling strong images of being "chained to the bed", and the "nightmare" of diagnosis and treatment. One possible interpretation is that the trauma has silenced her, and halted the possible process of transformation. Taylor (2000) noted that encountering darkness and suffering is requisite for transformation and, therefore, advises practitioners not to "discourage patients from encountering...pain and from asking the unanswerable" (p.787). From Judy's narrative, one could posit a need for her to open up to her suffering in order to move
forward and begin to form a coherent story of meaning. The role of the practitioner in this will be discussed in more depth below, along with the disconnect between body and self (Thomas-MacLean, 2004).

Frankl, in his book *Man's Search for Meaning* (2006) noted that "when we are no longer able to change a situation – we are challenged to change ourselves" (p.120), suggesting that his need for meaning kept him alive when was imprisoned in a Nazi concentration camp. According to Frankl (ibid), if the individual wants to survive, they must integrate their losses into their lives, re-establish their meaning and adjust to the new reality. However, the women's stories appear to confirm the conclusions of previous research of the nonlinearity and complexity of this transforming process (Carter, 1993). Arman and Rehnsfeldt (2003), after analysing past research on the lived experience of breast cancer, offer concern that breast cancer patients' experiences might have been misinterpreted in a reductive way. The importance of acknowledging the suffering and "the darker sides of experience" (Arman & Rehnsfeldt, 2003: 523) is supported by the stories in this study. For instance, we could reflect upon Caroline's narrative as expressing what Arman and Rehnsfeldt recognised as the initial tragedy stage of disintegration of earlier beliefs and vulnerability. From Linda's story, we could posit that she has been through and accepted suffering, and as a result of the accumulation of experiences throughout her cancer journey, she has begun to rearticulate her own story. However, the fact that none of the narratives follow a clear and easy change process emphasises the complexity of the phenomenon of integration and transformation. Moreover, the idiosyncrasies of each narrative implies a need for certain conditions and social situations to exist for transformations to take place, as expressed by Erikson's (1997) view of a suffering person's need for a significant other to take part in the 'drama of suffering'.

On a final note, it is perhaps important to consider the women's stories in the context of the dominant image of survivorship. Having outlined the criticisms of the dominant representations of breast cancer in Chapter 2, and noted Kaiser's (2008) attempt to offer alternative meanings, I will now reflect on this in light of the analysis of the four stories in this study. Whilst the 'restitution narrative', fitting with the 'survivorship narrative' of diagnosis, treatment and recovery, is a narrative that was apparent at times in some of the stories, these stories also hinted at uncertainties related to the experience of breast cancer. Therefore, although certain aspects related to the meanings or survivorship were embraced, such as concepts of winning a battle, contradictions must also be acknowledged. This
suggests the need for an awareness of the layers of meaning behind certain representations that might initially be introduced.

7.2.2 The physical experience of breast cancer and encountering medicine

As discussed in Chapter 2, feminist research questions the dominant assumptions in research concerning appearance and preoccupations with transitioning women's appearance quickly back to 'normality'. Langellier and Sullivan (1998) assert that, based on prior research, emphasis on the effects of a mastectomy replicate sexist power dynamics, which brings into question why literature on the negative aspects of breast cancer places emphasis on appearance and issues with feminine identity (Langellier & Sullivan, 1998; Wilkinson, 2000). Audre Lorde (1980) chose to reject a prosthesis following her mastectomy, noting that the medical language available to the ill homogenises their experience, and equating the prosthesis to forestalling a woman's acceptance of her new body, and thus, her new identity. Some research also suggests that when women speak for themselves about breast cancer issues other than breast loss are expressed as being important (Langellier & Sullivan, 1998). Taking this into account, it is interesting to consider what arose in the analysis of the four women's stories in this study surrounding appearance and talk around body issues.

Regarding the impact of breast cancer and the physical changes on feminine identity, Caroline reflects, "from a femininity point of view, I've been very accepting", to the point where she has gained weight and decided against wearing a prosthesis. Despite expressing acceptance of changes in appearance, Caroline also reflects that "my whole world was turned upside down", a complexity that is reflected in the findings of Langellier and Sullivan (1998) who found that, when 'breast talk' in women's narratives was examined, women constructed their narratives in a way that avoided a reduction of breast cancer experience to one that emphasises cosmetics and beauty culture. In fact, the experience of the body and of physical changes appears embedded in a larger life story (ibid). If we consider the narratives of the four women in this study in holistic terms, there is not a preoccupation with the stereotypical assumptions of femininity and sexuality, thus suggesting a far more complex experience. For instance, when considering Caroline's reflections on how she reacts to changes in appearance, what stands out is her disinterest in wearing a prosthesis or wig:

"I'm not bothered at all. I haven't bothered with a wig."
Although she expresses an uncertainty of who she will be and a sense of being in limbo, if we look at her reaction in terms of the feminist politics of visibility, silence, and the body (Herndl, 2002), one could perceive her decisions as possibly giving her body a voice, and an opportunity to explore a new identity. In 1980, Audre Lorde wrote of the silence surrounding breast cancer and mastectomy at that time, and about the falseness of prosthesis and reconstructive surgery. Whilst my study is over thirty years after Lorde's writings, the falseness of the cosmetic side of breast cancer is something that is expressed in Caroline's narrative:

"You don't need a bloody wig... I feel as though, if something is not me, then I don't want it... So with the prosthesis, it's not me, so I'd rather be lopsided."

Therefore, despite the time lapse, Caroline appears to be expressing concerns similar to Lorde. Although Herndl (2002) notes that today, breast cancer is no longer silenced in the way that Lorde experienced, from Caroline's story this does not appear to be the case. Her experience is one whereby she sees the social norm of wearing a wig as "taking advantage of somebody else's vulnerability". Perhaps this has to do with Caroline's recognition of change; to hide the physical changes would be to hide the other changes to her as a person. Similarly, Lorde (1980) argues that to refuse to acknowledge one's difference is to remain alien to oneself. Therefore, in both narratives there appears to be a conflict resulting from what Ellis (1998: cited by Thomas-MacLean, 2005) refers to as "common practices of concealing, underplaying, manipulating, or denying stigmatised differences" (p.161).

These concerns of silencing physical change related to breast cancer were acknowledged by Batt (1994) who warned of the emotional costs of projecting an image of health following cancer. I wonder about possible issues arising if a woman relies on a narrative focus on recreating a body that existed prior to breast cancer. Both Linda and Rosemary's narrative reflect striving for a physical appearance which does not show change resulting from breast cancer. For Rosemary, the concern is not of femininity, as she acknowledges that although she had reconstructive surgery, she is not concerned with appearance. Instead, her focus is on looking normal, with her narrative reflecting the benefits of not losing her hair, and therefore physically looking the same, rather than the benefits reconstruction resulting in her feeling feminine. This does not seem to attest to concern about beauty culture, perhaps due to Rosemary's age, something that she herself notes. Similarly to Rosemary however, Linda, a woman in her forties, focuses not on femininity and sexuality, but on looking 'normal'. Therefore, although often there is a suggestion of modern culture's "insistence on feminine beauty at any cost" (Herndl, 2002:153), in fact the
desire to deny illness appears to be more apparent in Rosemary and Linda's stories. It was not so much hiding breast loss, as hiding illness as a whole. Audre Lorde (1980) argued that restoring the normal appearance of being two-breasted simultaneously keeps women with breast cancer hidden not just from the other's gaze, but also from each other. However, the appearance of the breast was not the main concern in these women's narratives, highlighting a concern unrelated to dominant assumptions of femininity and body image, but instead of hiding sickness. Similarly to the findings of Langellier and Sullivan (1998), cultural associations of femininity with breast size, cleavage, and clothing were not primary issues for the women in this study. One interpretation is that women might make meaning of cancer as a chronic illness by adapting it to fit into their life as it was prior to illness, rather than concerning themselves with body image in terms of wholeness. However, even for Caroline with a primary breast cancer diagnosis, and only recently having experienced hair loss and mastectomy, the dominant cultural associations related to body image are not presented as primary issues for her.

The concept of suffering, as highlighted as an important consideration by Arman and Rehnsfeldt (2003), also arises in certain women's narratives of body talk. Past research found that some women asserted the ways in which the body can become objectified through treatments and the process of medicalisation (Thomas-MacLean, 2004), and I question the impact of the physical endurance of treatment on the body-self connection. Medicalisation is a social process involving the dominance of biomedical paradigms and the authoritarian models of health care, where illness experience is understood as biological and individualistic (Walters, 1994). Whilst a few qualitative studies have begun to critique the biomedical approach, thus beginning to emphasise the importance of women's words for understanding complex experiences such as breast cancer, researchers have tended to focus on singular issues such as breast loss, lymphoedema, and menopause (e.g. Bredin, 1999; Carter, 1997). In contrast, Thomas-MacLean (2004) focused on the medicalisation of breast cancer within a wider context, acknowledging the scope of breast cancer and survivorship as a "dynamic, life-long process" (Pelusi, 1997: 24; cited by Thomas-MacLean, 2004). Her research illustrates that encountering medicine involves the objectification of bodies, loss of autonomy, and suffering. Similarly, the stories presented in this thesis highlight tensions related to medical frameworks. For instance, within Judy's narrative, her body talk does not appear concerned with changes in appearance, instead expressing physical suffering. Although, like Linda and Rosemary, Judy speaks of an urge to get back to being normal and well, her words appear to tell a different story. She uses words that express a loss of physical agency and freedom, recalling having "canula's in my
groin, in my neck, all over the place", along with a memory of feeling as though she was "chained to the bed". Her physical freedom is lost to the extent that she recollects an inability to walk out of the hospital, or walk anywhere. If we take this strong visual image of imprisonment alongside Judy's predominant narrative focus on the external matters of health problems, diagnosis and treatments, there is an overall sense that the biomedical framework has caused a of loss of agency, to the extent that her voice has been taken away. Frank (1995) regards stories of suffering as having two sides: one that expresses the threat of disintegration, and a second that seeks a new integration of body-self. Judy's narrative appears to reflect a body-self disintegration as she expresses a recollection of having "an outer body experience looking down on myself."

Lorde (1980) expresses a view that medical language homogenises the experience of the ill, and one could posit that Judy's medical experience has in fact left her without language to express her experience and the meaning of these experiences. This is also illustrated by the way in which Linda and Rosemary begin their narratives with an account of their medical experience of breast cancer, fitting with ideas conveyed by Miller and Findley (1994), who have argued that we are held "hostage to modern medicine...which limits our ability to conceive of 'alternative frameworks' and definitions of problems" (p.302). A final aspect of medicalisation that became apparent from this research is the experience of different treatment from different consultants, as highlighted in Caroline's story. She expresses feeling anxious about gaps between medical treatments, perhaps feeling lost between health-care professionals. Her story appears to articulate the way in which the body becomes medicalised as an object that is passed between health-care practitioners, and one is left wondering where a person's sense of self and autonomy fits within this medical framework.

Upon reflection of the four women's narratives of bodily changes and the physical experience of breast cancer, it is apparent that research should continue to question the embodied experience of breast cancer. The narratives appear to point to the experiences of the body as related to the self, perhaps suggesting the importance of acknowledging the intersection of self and body (Thomas-MacLean, 2004). One might wonder first the reasons behind the desire to hide physical changes in order to maintain an appearance of normality to society, and then subsequently, the long term impact on the self of attempting to conceal the physical effects of cancer. As discussed previously, certain research has expressed concern of the emotional impact of pretending to be well by projecting an image of health to society (Batt, 1994). Frank (1995) asserts that the body needs a voice that
disease takes away, and I question how this voice can be heard if the self attempts to hide
the physical changes of disease.

7.2.3 Concluding remarks

From the above reflections of the issues that arose from the analysis, breast cancer is
highlighted as "a unique illness" (Thomas-MacLean, 2004: 638). The insights gained from
hearing the stories of these four women would likely have been lost through the detached
and abstract language of quantitative research stemming from a medical model. Miller and
Findlay (1994) reflected that we are "held hostage to modern medicine...which limits our
ability to conceive of 'alternative frameworks' and definitions of problems" (p.302); this
appears at times to be reflected when some women's narratives begin with a medical
account of facts about diagnosis and treatment. Whilst such a narrative of clinical
descriptions begin to paint a picture from a biomedical frame of reference, by looking
closer at the stories, insight into the unique experience of breast cancer is gained. As noted
by Langellier and Sullivan (1998), narratives suggest ongoing stories-in-progress that
involve a renegotiation of body and self. Therefore, by considering body talk in the
context of individuals' lives as a whole, health care research can continue to recognise the
varied narratives occurring behind the medicalised world of cancer and the dominant
assumptions existing within the social context.

Whilst I presented 'changing sense of self' and 'body talk and appearance' as two separate
issues that arose from the analysis of the stories, I consider them to be interconnected.
From the above discussion, I hope to have highlighted the importance of listening to stories
holistically; rather than seeing a separate body and a self, I would assert the benefit of
continuing research into narratives as body-self stories, whereby "reclaiming begins with
(the) body" (Frank, 1995: 65). The relations among women's bodies and selves are
complex, multiple and sometimes contradictory; new understanding can perhaps be
appreciated in research that acknowledges the body and self holistically. Reflecting back
to the reference to Frank, introducing 'The Genesis of the Study' in Chapter 1, the physical
injuries "become a source of potency of their stories" (1995: xii).

In the sections below, I will discuss how the field of counselling psychology might meet
the psychological needs of women with breast cancer. The stories of the four women in
this study suggest an ongoing process of meaning-making in the context of multiple
changes. I posit that through the use of metaphor, women are able to articulate and make
meaning. I will first begin by reflecting upon the initial justification of the research, in
order to relate this to a counselling psychology perspective.
7.3 Justification revisited

In this section, I will return to the introduction, whereby I justified this research based on personal, practical and social justification (see Clandinin & Huber, 2010), considered to be salient design considerations for a narrative inquiry. The issues that arose from the analysis will be considered in the context of how the research evolved. First however, I will remind the reader of the context from which this study stemmed. In terms of a personal justification, my motivation to carry out a narrative inquiry of experiences of women with breast cancer arose from a dissatisfaction with research stemming from a medical model of classifying patients according to emotional reactions, whereby the 'problems' of cancer patients are the focus of the research (Mathieson & Stam, 1995). My own reflections as a trainee counselling psychologist working in a cancer hospital was the way in which a changing sense of self was often at the forefront of therapeutic work. The idiosyncrasies of such changes have been highlighted in the women's narratives in this study, but would likely have been difficult to access through quantitative, large scale research.

From a practical justification design consideration, the stories of women with breast cancer may be helpful for the enhancement of the work of counselling psychologists in the field of psycho-oncology. With social justice being one of the core values of counselling psychology (Packard, 2009), I consider the field of psycho-oncology as one in which we can work therapeutically with people who have experienced cancer, offering a space in which they can liberate themselves from the role of patient. Finally, from a social justification perspective, it is important to acknowledge the experience of cancer in a modern society. As a result of advanced medicine, cancer is more often being experienced as an intermittent and chronic condition, with the 'remission society' being a modern concern (Frank, 1995). Insight can be gained through stories, with storytelling offering a way of developing current discourse, with possibilities of questioning prevailing assumptions.

Taking into account the genesis of this study, I listened to and presented stories of four women, with the hope to make the voices of women who have experienced breast cancer available to the discipline of counselling psychology. I will now reflect on the way in which the justification fits with what arose in the analysis of the four women's stories.
7.4 Meeting the psychological needs of women with breast cancer

Following the above discussions about the impact of breast cancer on the women in this study, I turn now to a discussion of how the discipline of counselling psychology might meet the psychological needs of women with breast cancer. Narratives in this study suggest that problems related specifically to physical attractiveness are not at the forefront of women's concerns, with issues of control, agency, and restitution being more prevalent. Despite over thirty years passing since Audre Lorde wrote *The Cancer Journals* (1980), issues of a body silenced and dissociated by medicine still appear apparent, suggesting a medical language that homogenises the experience of the ill. George et al (2014) in their editorial on the Liverpool Care Pathway for the Dying (LCP) note that throughout the 21st century in the United Kingdom, engagement with the meanings of people's distress was overwhelmed by a default to medical diagnostics, drugs and a hierarchical biomedical model.

In 2000, the NHS Cancer Plan noted the importance for care pathways for cancer to be 'individualised' to that person's unique journey, covering referral through diagnosis to treatment(s) (National Cancer Plan, 2000). Reflecting on this, I am reminded of Caroline's comment:

"I think now about support and counselling. I felt quite anxious when I went to see the surgeon and she told me I was doing really well, that everything looked fine, and that she would see me in six months. It was a shock; I didn't know what to do. I think that with the whole cancer thing, there are gaps in your care. You have your own doctor to deal with physical day to day symptoms, then you have your oncologist who has your regime of your chemo, and then there is your surgeon. But then there are little gaps in between, because the three don't speak to each other. So they don't see you as one person. To one person, you're a chemo patient, to another you're a GP patient."

From this reflection, I wonder if the requirement for healthcare professionals to integrate the biological and medical needs with the human needs for meaning, comfort and direction (Main, 1990) is a difficult thing to fulfil. I therefore begin by discussing the perspective of counselling psychology, and how it might offer something towards the care pathway discussed above. I will then consider the way in which women in this study appear to make meaning through the use of metaphor, and how this could potentially be used from a therapeutic perspective.
7.4.1 Psycho-oncology: a counselling psychology perspective

The stories presented in this chapter highlight the importance of a person's narrative, telling their illness stories in order to gain meaning and new perspectives. Like Collie and Long (2005), I conclude that, based on the complex and contradictory meanings expressed by the women in this study, it would not be helpful for clinicians or others to promote a particular kind of meaning making for women with breast cancer. Moreover, Taylor (2000) noted that encountering darkness and suffering are requisites for transformation. Therefore practitioners are advised not to "discourage patients from encountering...pain and from asking the unanswerable" (p.787). Reflecting on narratives that express a need to maintain image of health, and the potential emotional price for projecting what Caroline refers to as 'false' image (Batt, 1994), I posit a potential need for more opportunities to encounter what Arman and Rehnsfeldt (2003) refer to as "the darker side of suffering" (p.524). As counselling psychologists, there is a call to embrace social justice-oriented work (Packard, 2009), described by Goodman et al (2004) as 'giving voice', 'facilitating consciousness raising', and 'leaving the client with tools to work toward social change'. Such principles are in keeping with Frank's (1995) view of stories as a way for ill people to reclaim the self, and give the silenced body a voice.

An awareness of individual narratives surrounding appearance and physical change is something I would consider important for a therapeutic relationship to develop. I am reminded of the narrative of Clara Larsen, used by Klawiter (2004) to explore changes over time in the experiences of illness. Clara's first narrative occurred in the 70's, recounting a time of male, heterocentric assumptions focusing on physical attractiveness and hiding evidence of surgery with breast prostheses. Despite the time lapse, both Rosemary and Caroline's narratives reflect a medical environment in which it is assumed that women will wear a prosthesis and/or have reconstruction. Caroline expresses explicitly a rejection of the prosthesis and wig, whilst Rosemary reflects that she in fact regrets having reconstructive surgery, but "just went along with it", suggesting an assumption of the medical world that women will naturally want reconstruction. As therapists, it is important to be aware of the potential confusion and struggle between individual needs and social norms. Considering this in terms of social realities, this is not something that we can remove or alter. We can, however, offer opportunities to provide a reflective space for more women with breast cancer to tell their own stories, rather than fracturing accounts into thematic categories as is the tendency of much qualitative research, whereby the women's private perspectives are lost (Bredin, 1999).
With the need for normality expressed by three of the four women (Linda, Rosemary and Judy), perhaps one role of the therapist may be to collaboratively work with patients with cancer to find the 'new normal', by accommodating and reframing the loss. Osborn (1998) notes that in cases where people are struggling to accept changes, some perceptions of the old self can still be recognised and maintained, offering a source of hope in a potentially traumatic time. Moreover, therapy could encourage a focus on what they can control in their lives (Harris & Jsenor, 2011), a need that appears to be expressed in Linda and Rosemary's stories. For example, in Rosemary's story she may be perceiving herself in terms of the micro-level of her life, acknowledging the control she has in the day to day of her life, in terms of how she interacts with others, and the responsibility she has for her animals. As therapists, perhaps we can learn from Rosemary's story; although she recognises and accepts the uncontrollable parts of her life, she also is able to focus on the controllable parts of her life, which perhaps explains her high resilience. Therefore, a suitable therapeutic approach might focus on opening up to suffering (Arman & Rehnsfeldt, 2003), with an aim to reach a level of acceptance, as opposed to denial of illness and suffering. Rehnsfeldt (1999: cited by Arman & Rehnsfeldt, 2003)) speaks of the need for health care practitioners to enter an existential caring encounter, where suffering is permitted and the suffering person is cared for in safe surroundings.

Taking the above into account, I will now consider the therapeutic use of metaphor in counselling to help clients to encounter suffering and make meaning from the experience of breast cancer.

7.4.2 Meaning-making and metaphorical talk

Susan Sontag (1978) speaks of cancer as the predominant disease metaphor in our culture, arguing that it is in fact unhealthy to think metaphorically of cancer. She uses the 19th century view of insanity as one example of malignant metaphoric thinking, concluding that as we learn more about the etiology and treatment of cancer, its metaphorical system will die. However, in her essay, she does not seem to consider the way in which metaphoric thinking is a way to discover meaning in our lives. Within the stories of the women in this study, metaphor features significantly, and as I consider the use of metaphor used by the four women in this study, I relate back to the first research question:

*What insights do women's narratives provide regarding how they make meaning from their experiences of breast cancer?*

From this, I reflect upon the following quote:
"Metaphor may be seen as an all-terrain vehicle carrying the therapeutic process off the paved roads of prior meaning structures out into unchartered territories where new meanings are yet to be created" (Lyddon, Clay & Sparks, 2001: 273).

As counselling psychologists, under the Health and Care Professions Council, there is an expectation to "understand how empathic understanding can be helped by creativity and artistry in the use of language and metaphor" (HPC, 2009: 10). Moreover, in keeping with the social justice work of 'giving voice' (by providing a space in which women can express their own accounts) and 'facilitating consciousness raising', two principles encouraged in the field of counselling psychology (Goodman et al, 2004), metaphor can perhaps be utilised therapeutically to encourage storytelling and offering a voice. It is perhaps fitting, therefore, that the women in this study spontaneously introduced the use of metaphor when telling their breast cancer stories, implicating the importance for practitioners to be open to the creative construction of meaning and thought. However, if we as health care practitioners are to engage with patients through the use of metaphor, it is important that we get it right. For instance, Lance Armstrong, in It's Not About the Bike: My Journey Back to Life (2000) recalls his oncologist using metaphorical language related to war, such as 'killing' and 'hitting', which caused him to feel alienated and devastated, as opposed to empowered. Therefore, when using metaphors to discuss the illness with patients, health care professionals should take care of how we relate meaning to metaphors.

There has been a great deal of work in recent years considering the way individuals use metaphor in talking about their experiences of illness. Many studies have shown that patients routinely use a wide range of metaphorical expressions as they talk about the subjective experience of illness (Gibbs & Franks, 2009). In relation to the meaning-making process, it is evident that illness brings with it the need to make sense of what is happening to someone, and metaphor can provide a tool for this transformation of meaning. As discussed, this is evident in the complex and multilayered way in which the women in this study tell their cancer stories. As with the philosophy of this study, metaphor moves away from logical knowledge and understanding (Lyddon, Clay & Sparks, 2001) associated with the 'paradigmatic mode' of thought (Bruner, 1990), comprehending experience in terms of tightly reasoned analyses, logical proof, and empirical observation. Moreover, metaphor fits with the narrative interests of this study. Bruner (1990) notes that stories mean more than they say and metaphor can compliment this mode of thought to the extent that they are:
"a way of speaking in which one thing is expressed in terms of another, whereby this bringing together throws new light on the character of what is being described." (Kopp, 1971: 17: cited by Lyddon et al, 2001)

In one study, Gibbs and Franks (2009) analyse metaphors introduced spontaneously by six women in their narrative of their experiences of cancer, and found consistency with the arguments of many scholars and health professionals who note the essential importance of metaphor in aiding people to make sense of illness and offer answers to the existential question, "Why me?" (Schepers-Hughes & Lock, 1986: 139: cited by Gibbs & Franks, 2009). Taking this into account, metaphor is also of relevance in the context of counselling and psychotherapy, with regard to the role it may play in facilitating change processes; offering a way of understanding, communicating, and, therefore, symbolically controlling their illness by giving women a way in which to give their bodies a voice to express the breast cancer experience (Reisfield & Wilson, 2004). Moreover, Lyddon, Clay and Sparks (2001) note that there is much support for the use of metaphor in counselling, in its ability to provide an effective mode of communication and meaning-making.

Metaphor in stories invites the listener to go beyond the rational, to a place of implicit knowing (Mills & Crowley, 2001). Considering these findings in the context of the women in this study, I wonder what we can learn from the way in which metaphor is used in their stories.

Rosemary and Linda use what Reisfield and Wilson (2004) refer to as a 'martial metaphor', implicating a meaning of breast cancer as something to fight and beat. However, in this case, the enemy in this war is in the self (Reisfield & Wilson, 2004). Therefore, when working therapeutically with metaphor, an awareness of hidden meanings and conflict within a person's surface narrative is vital. Moreover, a similar narrative might be used to express contradicting meanings. For example, whereas Linda's words refer to dictating cancer from an empowering stance, Judy rejects the traditional war imagery of bravery, noting that in fact she has no choice. Similarly, when Caroline engages with the war metaphor by reflecting on being "a ticking time bomb", this also implies a lack of choice or control. This brings into question whether the use of metaphor is always an experience of gaining control and meaning from an experience, as Reisfield and Wilson (2004) suggest. In relation to the prison metaphor employed by Judy, imagining herself to be "chained to the bed", perhaps reflects a lack of control, being thrown into crisis. However, consider for a moment Arman and Renhsfeld's (2003) recognition of the way in which researchers often imply a process of transformation that is quick and easy, ignoring the suffering that might
be occurring. Although Judy perhaps expresses, through the use of metaphor, disempowerment in the context of cancer, there is opportunity to feel empowered through the use of metaphorical language, accessing emotion and thought that might otherwise have been left untouched. Therefore, research that takes note of the way in which women's stories employ metaphor perhaps has the potential to embrace unique aspects of individual stories, rather than general representations. In the case of Judy's metaphor of imprisonment, arguably what is being communicated is the complexity of the experience of breast cancer. If her story was engaged with on a surface level, a story of diagnosis, treatment and results may be heard, with very little about the impact of the experience on her sense of self. However, by observing metaphor, researchers and practitioners may engage with the aspects of a person's story that may otherwise be difficult to put into words.

When considering the journey metaphor employed by some of the women, a metaphor particularly applicable to cancer being seen as enmeshed in life, as a chronic illness (Reisfield & Wilson, 2004), certain aspects of the social experience of cancer appear to be revealed. For instance, Caroline reflects on her life being on hold as a result of cancer, and waiting to "get the green light" before recommencing her original life journey. Reflecting on the metaphor of a green light suggests normative rules that driving relies upon, whereby lights control the drivers choices, thereby implicating Caroline being restricted and controlled by an external force of medicine. Engaging with metaphor, therefore, facilitates alternative meanings, by exploring and expanding present understandings (Fox, 1989: cited by Lyddon, Clay & Sparks, 2001). It is an understanding that is separate to empirical and logical knowledge (ibid). Moreover, metaphor has been conceived as being processed on a multisensory level, so they "capture vivid representations of experiences" (Etherington & Bridges, 2011: 12), and are in fact closer to our actual experience. For this reason, by listening for the use of metaphor in stories of women with breast cancer, there is perhaps potential for researchers and practitioners to elaborate and deepen the understanding of the internal experience of having breast cancer.

In this section, I have suggested that metaphors play a significant role in the construction of meaning, and the development of stories. I reflect once more on the following research question:

*What insights do women's narratives provide regarding how they make meaning from their experiences of breast cancer?*
Metaphor has been found in past research to be employed to make sense of illness, and in this research, although none of the women introduced metaphor explicitly, all four women used multiple metaphors to construct the complexity of meaning related to the experience of breast cancer. These meanings ranged from viewing cancer as something to beat and fight, both as a separate entity and also as a part of the self. One woman drew on a metaphor of imprisonment, whilst others continued along a journey, albeit an altered and restricted one. Metaphor was used to express both empowerment and disempowerment. Whatever the metaphor employed, they appear to be a powerful way of accessing thought and emotion when telling a story. Therefore, by engaging with each individual’s creative style of metaphor, counsellors and psychotherapists have the opportunity of speaking metaphorically with clients in a very personal and meaningful way. Reflecting back to the psychological needs of women with breast cancer, what was apparent in much of their talk was the link between bodily experience and the impact of this on the women’s sense of self. That metaphors are often embedded in reference to the body can enable clients and counsellors to elaborate on internal experiences (Robert & Kelly, 2010), something of importance for women who have gone through physical changes and suffering. Metaphor can also increase a client’s awareness of their emotions and their level of emotional arousal (Lyddon, Clay & Sparks, 2001), potentially allowing women to engage better with the changes experienced through breast cancer.

Although much of the above seems to be about how the women used metaphor to express the meanings they make when telling their cancer story, the therapeutic power of metaphor seems to be grounded in its power to facilitate change. Metaphors enable the expansion from existing experience and knowledge to new unfamiliar areas and possibilities (Lyddon, Clay & Sparks, 2001), therefore using metaphor to meet the psychological needs of women with breast cancer has the potential to explore and engage with new realities. Through this, perhaps there is the potential for women with breast cancer to gain a voice, and develop a deeper consciousness surrounding the meanings of their experience.

Whilst the metaphors employed and discussed in Chapter 5 are just one interpretation, by opening up a discussion with a client, and allowing them to become more aware of their metaphorical experiences and expressions, there is potential for the client to become empowered to critically examine them (Lyddon, Clay & Sparks, 2001).

7.5 Conclusion

I hope in this chapter to have highlighted the way in which listening to stories can stimulate new ways of understanding of the experience of breast cancer, and the meanings
made of such an experience. In keeping with the set of principles derived from feminist counselling theories that counselling psychologists could consider when engaging in social justice work (Goodman et al, 2004), a narrative study such as this is aimed to 'give voice' and 'facilitate consciousness raising' (ibid) through telling stories and being heard. As discussed, despite a wealth of literature reporting on the impact of breast cancer, most studies focus on categorising narratives into themes that run across the stories, rather than directly quoting an individual's private perspective. The essential meanings and psychological needs of women "can be grasped only by listening to the women themselves" (Kasper, 1994: 266). Consequently, I hope to have discussed such needs based on the words of the women themselves, rather than in terms of generalised themes.
Chapter 8

Conclusion

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8.1 Introduction

This study aimed to explore four women's experience of breast cancer to gain new insights into the meaning-making processes, both supporting and expanding on past research. This concluding chapter summarises the purpose of this study, and discusses the findings and key issues, along with the limitations of the study. Finally, potential contributions to the field of counselling psychology will be presented along with recommendations of future avenues of research that might offer a further development of our understanding of women’s experience of breast cancer.

8.2 Purpose of the study

The purpose of this study was to explore how women with breast cancer make meaning of the experience. The intention was to approach this exploration from the standpoint of the discipline of counselling psychology, hoping to maintain the humanistic values of the discipline and, therefore, striving to enhance the psychological support offered to women with breast cancer. Coming from the perspective of valuing the enhancement and promotion of the welfare of others (Packard, 2009), I hoped to continue to develop an environment that embraces the subjective process of meaning making.

An unstructured narrative framework was used, offering each woman one main orienting statement 'I am interested in hearing your cancer story and your own personal experiences'. Following the perspective of Kasper (1994), I hoped this would allow each woman to express their own stories, acknowledging varying life experiences and the intricacies of individual stories.
8.3 Narrative framework: the methodology

My choice to follow a narrative framework was based on the aim of the study: to gain meaning from the women's stories and how they perceive themselves and their lives. Inspired by McAdams reflection that "good stories give birth to many different meanings" (1993: 3), I chose a narrative framework in the hope to explore the multiple meanings women made of the experience of breast cancer. Central to the methodology of this study is the belief that in order to grasp the meanings women make from their experience we must listen to the women themselves, hence why an unstructured narrative interview was chosen.

A narrative approach to both data collection and analysis has allowed me to critically investigate and interpret individuals' construction of meaning (Riessman, 2008). Throughout the research process I attempted to come from a perspective of subjectivity, where the participant's narrative is the most significant aspect of the research. However, I also acknowledged through reflexivity, my contribution to the formulation of the research, and, as an active listener, to the data.

8.4 Limitations to the study

When reflecting on the potential limitations of certain aspects of this thesis, one particular aspect is the small number of participants. Having discussed frequently with my supervisor the question of 'how many interviews is enough?' my initial intention was to interview six women. However, after I met the first four women I became aware of the depth of detail to each story, and taking inspiration from Baker and Edwards's paper, for the National Centre for Research Methods, *How many qualitative interviews is enough? Expert voices and early career reflections on sampling and cases in qualitative research*, I concluded that the number of participants is dependent on the scope and intention of the study. Using a narrative methodology each story was detailed and in-depth, and I wanted to avoid brief analysis. Instead of approaching analysis searching for breadth and generalisation, I hoped to acknowledge the intricacies and complexities of each of the woman's narratives. As psychologists I see a necessity in 'giving voice' to others (Packard, 2009; Goodman et al, 2004) by continuing to document the diversity of women's experiences. In this context, the number of participants is somewhat irrelevant, as each voice is valued in its own right, not as a way of producing thematic categorisations.

A further potential limitation of this particular study is related to the changing meaning throughout the process of story-telling. The four women's narratives show contradictions
and discrepancies, something which Reinhartz regards as revealing "the complex process of the construction of reality" (1981: 82). If meaning is made throughout the process of telling stories, (Langellier & Sullivan, 1998), therefore I would suggest that deeper insights might have been gained into the development and change of meanings had I carried out follow-up interviews. Despite this being somewhat of a limitation, I would posit that some insight was gained regarding the impact of additional diagnoses and treatments, due to the different stages of breast cancer each woman was at.

8.5 Summary of insights from the literature and the findings

Examining the narratives of the four women showed a diversity of experience is apparent, and whilst the intention is not to summarise and generalise, I will offer what I consider to be the significant points from this research. These can be identified as follows:

- Transformation processes are varied and non-linear
- Women's stories oscillate between different 'narrative types' of quest, restitution and chaos (see Frank, 1995). Therefore, it is important to ensure individual meaning over categorisation is acknowledged
- Meaning making and transformation processes are influenced by previous life experiences
- Encountering darkness and suffering is an important aspect of forming meaning and reintegrating body and self
- The experience of physical changes are embedded in a larger life story
- The cosmetic side of breast cancer has the potential to silence the possibility for change and transformation
- Within some stories there is a desire to deny illness. From this study, this appears to be the main concern, as opposed to a desire to look feminine and attractive
- Women used metaphor to express contradicting meanings, and concepts that might be difficult to express through logical and empirical language.

8.6 Summary of the key implications of the thesis

In an attempt to summarise the main significant points that came from the current thesis, the following key implications can be identified:

- There is an importance for practitioners to encourage encountering of suffering and offer a space in which existential questions can be explored
• There is a need for a care pathway that incorporates the need for meaning and direction into the biomedical model (also see George et al, 2014)

• In relation to Batt's (1994) warning of the potential emotional price for projecting an image of health following illness, there is a potential need to facilitate 'consciousness raising' (see Goodman et al, 2004) following physical changes that occur throughout breast cancer treatment. This could be achieved through a therapeutic approach that focuses on acceptance rather than denial of illness and change

• Health care professionals working therapeutically with women with breast cancer need to have sensitivity to appearance and physical changes, and the complex meaning women make of this

• As therapists, it is important to be aware of the conflicting views surrounding reconstructive surgery, and wearing prostheses and wigs. From this study it seems necessary to 'give voice' to alternative responses to physical changes, that might not fit with dominant social assumptions

• Collaborative reformation of a 'new normal': by working narratively with women with breast cancer, change and loss can be accommodated and reframed into a new story

• The therapeutic use of metaphor: the utilisation of metaphor has the potential to encourage storytelling and offering a voice. Moreover, the fact that metaphors were used spontaneously by all four women when telling their stories suggests their therapeutic power to stimulate growth and change (Guiffrida et al, 2007).

These research findings have direct relevance to my role as a counselling psychologist with an interest in giving voice in a therapeutic setting, advocating a promotion of the welfare and psychological needs of women with breast cancer. I hope this research provides a good foundation of knowledge to deepen our understanding of the possible role for counselling psychologists in the field of psycho-oncology.

8.7 Further considerations

The stories from this research can form a foundation for similar research from a counselling psychologist’s perspective, potentially developing these findings by use of a more diverse sample, as the four women in this study were all white, middle class, married women, and seemingly from similar socio-cultural environments. Listening to stories of women from different cultures and sexual orientation is an important aspect of feminist research and something that counselling psychologists ought to embrace in order to
provide a space to women coming from different social experiences. As noted by Kitzinger and Wilkinson (1997), 'women' are not a single and unitary category, and this must be continually acknowledged when researching women's experience. Consequently, being part of feminist research means continuing to respectfully challenge dominant assumptions and taken for granted experience (Kitzinger & Wilkinson, 1997).

Finally, in this piece of research, the women I met had been introduced to me by their consultant as they were deemed 'psychologically fit' to engage in discussions around a potentially distressing topic. This was an important aspect of the university ethical clearance procedure. Although it has ethical implications, and such research would need to be carried out sensitively, hearing the stories of women in distress is also important, and I would posit that it is in fact unethical to ignore such stories.
REFERENCES


British Psychological Society (2010). Ethical Principles for Conducting Research with Human Participants.


Clark, D.  (1997). What is qualitative research and what can it contribute to palliative care? *Palliative Medicine, 11* (2), 159-166.


Lacey, J.V. Jr. (2009). Breast cancer epidemiology according to recognized breast cancer risk factors in the Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial Cohort. BMC Cancer, 9, 84.


INFORMATION LETTER

Dear potential participant

My name is Emily Cudworth and I am currently working on my Doctorate in Counselling Psychology at the University of Manchester. You are being invited to take part in a research study that will form my thesis for the Doctorate. Please take time to read the following information carefully which explains why the research is being done and what it will involve for you. There will be an opportunity for me to go through the information sheet with you and answer any questions you have. Contact details are provided at the end of the information sheet. Please take some time to decide whether or not you wish to take part. Many thanks.

If you agree to be one of the 4 participants, I will ask you to participate in a non-structured interview regarding your experience of illness.

What is the aim of the research?

The aim of this research is to explore the ways in which adult women experience their identities altering throughout breast cancer treatment, and the effect this has on the experience of breast cancer diagnosis and treatment.

Why have I been asked to participate?

You are being asked to take part as you are a patient at The Christie Clinic, it is important to remember that this is not a compulsory part of the treatment at The Christie Clinic.
What would I be asked to do if I took part?
If you agree to be a participant, I will ask you participate in one interview. I will ask you simply to tell the story of your cancer experience. The length of the interviews will be dependent on how long you feel comfortable talking but will be no longer than an hour and a half and will include breaks whenever necessary. The session will be audio recorded and subsequently transcribed for analysis. As the emphasis in narrative inquiry is on each individual's meaning made from an experience, I will return the transcripts to you to give you the opportunity to censor and also confirm that the correct meaning has been achieved.

What if I feel the need for subsequent support following the interviews?
If you feel the need for subsequent support, a counselling service will be made available at The Christie Clinic.

What happens to the data collected?
The audio recording will be deleted after transcription and the electronic document containing the transcription will be kept in an encrypted file. Any paper copies will be kept in locked storage. Only the researcher will have access to the transcribed session. Some quotes may be used in the write-up of the research, but these will be in no way identifiable: where there is uncertainty, the researcher will check this with you. You will also be given a chance to see the data analysis should you wish.

How is confidentiality maintained?
All efforts will be made to ensure that confidentiality is maintained. As mentioned above, the electronic data will be kept in encrypted files and there will be no identifiable information contained within the write-up of the report. Any hard copies of the transcript will be kept in locked storage. You will be referred to by a pseudonym in any written reports and any quotes used will be non-identifiable. These safeguards are in compliance with the University of Manchester regulations on data protection.

What happens if I do not want to take part or change my mind?
Participation in this research is voluntary and you can choose not to take part in the research. If you do agree to take part there will be a number of points where you will have the opportunity to change your mind if you wish. If you sign the consent form but then change your mind at any point in the session being recorded you can withdraw from the research. Additionally in the following session you can withdraw if you have thought about it and changed your mind. Finally, you can change your mind and withdraw from the research after reading the analysis of the data, if you choose to see.
What is the duration of the research?
There will be two sections of the interview, the duration of which will be dependent on how long you feel comfortable talking.

Where will the research be conducted?
The research will be conducted in a predetermined room at The Christie Clinic.

Will the outcomes of the study be published?
The outcomes of the study will form part of a University assessment, and there may be further publications in academic journals. As detailed above, in these publications there will be no identifiable information written about you.

Contact for further information
If you are interested in participating in this study, or would like more information, please contact me at my e-mail address: emily.cudworth@postgrad.manchester.ac.uk or on the following telephone number: 0161 275 8627.

What if I wish to make a complaint?
If there are any issues regarding the research that you would prefer not to discuss with members of the research team, please contact the Research Practice and Governance Co-ordinator by either writing to 'The Research Practice and Governance Co-ordinator, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL', by emailing: Research-Governance@manchester.ac.uk or by telephoning 0161 275 7583 or 275 8093.

I look forward to hearing from you.

Yours sincerely
Emily Cudworth

Supervisor:
Richard Fay, The University of Manchester
Email : richard.fay@manchester.ac.uk
Phone : 0161 275 8627
**APPENDIX B**

**Transformation of perceived female identity throughout breast cancer treatment: A narrative study**

**Consent Form**

If you are happy to participate please complete and sign the consent form below

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<td>**Table</td>
<td>Description**</td>
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<tr>
<td>1.</td>
<td>I confirm that I have read the attached information sheet on the above project and have had the opportunity to consider the information, ask any questions and have had these questions answered satisfactorily</td>
</tr>
<tr>
<td>2.</td>
<td>I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason, and that withdrawing from the research will have no negative effect on my treatment at The Christie</td>
</tr>
<tr>
<td>3.</td>
<td>I understand that the interview sessions will be audio recorded and transcribed</td>
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<tr>
<td>4.</td>
<td>I agree to the use of anonymous quotes in any write up</td>
</tr>
<tr>
<td>5.</td>
<td>I agree that any data collected may be published in anonymous form in academic books or journals</td>
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I agree to take part in the above project:

<table>
<thead>
<tr>
<th>Name of participant</th>
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APPENDIX C:

Further examples of the restorying process outlined in Chapter 3

Extended Excerpt from the Transcript of Caroline's Narrative

CW:......Well this came completely out of the blue....

EC: ...mmhm

CW: .....as I'm sure in most case....erm...my back ground, I suppose the build up to it, is I'm...erm... a professional, a director.....a global director of a big company....erm...and I'm only one of one women in the whole world who does the role...

EC: ...ah ok...

CW: ...so....I've kind of personally achieved an awful lot...

EC:.....Yeah

CW:...and...a lot of that was about how you look...

EC: ...ahah

CW: ....erm...you know, being strong being powerful, being able to – I investigate fraud so....

EC: ...ah ok...

CW: ...so it's a very difficult environment...

EC: .....one where you're quite in charge?

CW: ....yeah...and erm...so for me it's all about the whole package, how you look, how you present yourself – I do a lot of speaking at conferences, and lecturing around the world, and then I get this news....and of course I'd only been with the company I'm with twelve months to the day...

EC: ....ah

CW: ......when I got diagnosed.

EC: Ok...
CW: So erm, it was a case of trying to come to terms with the...the er the disease and at the same time my whole world was tipped upside down, because I'm away from home probably erm at least four days a week, I travel extensively around the world so to be thrust back into....

EC: ...mmm

CW: ...that environment....

EC: ...so quite a role reversal?

CW: A complete role reversal. So it wasn't just the cancer, it was, everything stopped, everything changed..

EC: ..mhmm

CW: ...overnight – literally overnight. Erm, and my diagnosis was....I was diagnosed on the 9th of January and by the 20th I'd had my mastectomy, and my lymph nodes removed – it had gone to my lymph nodes – so erm....it was....I didn’t have really a lot of time to get used to the idea...erm....so from the point of view of my myself, I'm a very, I think I'm a very strong person..

Step 2: Extended Excerpt from the Restorying Draft of Caroline's Narrative

Well this came completely out of the blue as I'm sure in most case. My back ground, I suppose the build up to it, is I'm a professional, a director, a global director of a big company, and I'm only one of one women in the whole world who does the role. So I've kind of personally achieved an awful lot. A lot of that was about how you look, you know, being strong being powerful. I investigate fraud it's a very difficult environment. So for me it's all about the whole package, how you look, how you present yourself. I do a lot of speaking at conferences, and lecturing around the world, and then I get this news, and off course I'd only been with the company I'm with twelve months to the day when I got diagnosed. So it was a case of trying to come to terms with the disease and at the same time my whole world was tipped upside down, because I'm away from home probably at least four days a week, I travel extensively around the world so to be thrust back into that environment. A complete role reversal. So it wasn't just the cancer, it was, everything stopped, everything changed overnight. I was diagnosed on the 9th of January and by the 20th I'd had my mastectomy, and my lymph nodes removed – it had gone to my lymph nodes. I didn’t have really a lot of time to get used to the ide .so from the point of view of my myself, I think I'm a very strong person.
Step 3: Excerpt from the Final Restorying Draft of Caroline's Narrative

The Diagnosis

It all came completely out of the blue for me, as I'm sure it does in most cases. The build up to this is the fact that I am a professional, a global director of a big company, and the only woman in the world who does this role. I've personally achieved a lot in a difficult environment, in which appearance and being strong and powerful is important. So, for me it was all about the whole package and how you present yourself, as I do a lot of speaking at conferences and lecturing around the world. When I got the news that I had cancer I had only been with the company I'm with for twelve months. So my whole world was turned upside down. It wasn't just about having to come to terms with the disease, everything stopped, and everything changed, overnight. I was diagnosed on January 9th and by January 20th I'd had my mastectomy, and my lymph nodes removed. Although I didn't really have a lot of time to get used to the idea, I think I'm a very strong person and I haven't cried over this at any point.

Excerpt from the Transcript of Rosemary's Narrative

CH: Erm...well I've never had really time to think about things cos I was always working. I worked long hours you see.

EC: Ok.

CH: So I had this cancer first fourteen years, was it fourteen years, ago now.

HH: ....Fourteen years yeah...

CH: And it came back after fourteen years.

EC: mmmm.

CH: So...I really...erm, sort of jumped straight into erm....my, what I had to have done. You know, my treatment and that. I didn’t really have time to erm to think about it really because I was working full time...

EC: ...ok...

CH: ...and erm, I did long hours didn’t I Harry?

HH: mmm.
EC: What did you used to do?

CH: I used to work in a library, and we used to work like 9 till half seven.

EC: Oh wow, ok.

CH: But erm, I've always been erm...on the move. You know what I mean?

EC: mhm, yep, active?

CH: Active, yep. So erm, I didn't really have time. Anyway, when I went to erm, Thameside it first was wasn't it?

HH: mmm, yeah, first time.

CH: First time, erm, I had it.

EC: mmm.

CH: Erm...

EC: So this was, just to get the facts right, that was the fourteen years ago?

CH: Yeah, yep, erm. I just said to them...They said, you've got cancer. And erm, I knew they were going to tell me that because erm, there was always a nurse going in wasn't there? I recognised....

HH: ...I noticed it....

CH: ...the people that had cancer, there was always a nurse going in. So it was a give away.

EC: Ah really, so that must have been quite a....almost waiting, know that you're going to...

CH: It was, yeah. I knew, I knew before I got in....

HH: ...yeah....

CH: ...so when I got in he said, it's cancer, you've got to have a mastectomy. I said fine, I just said fine, cos I'd already realised before I got in.

EC: Ok, so before you'd got in that door, you'd almost told yourself?
CH: Yeah, because, when I was going for a scan, I was looking at all the faces, and I could tell with the faces....

EC: mmm.

CH: ....that there was a problem.

EC: So what gave it away? Their faces changed in some way?

CH: ...their faces changing. I always look at people's faces and I could tell. I knew straight away what I was going to be told. So I had a bit of time. And...then I went back to the car, to sit in the car while I was waiting to see the consultant.

Step 2: Excerpt from the Restorying Draft of Rosemary's Narrative

Well I've never had really time to think about things cos I was always working. I worked long hours you see. So I had this cancer first fourteen years, was it fourteen years, ago now. And it came back after fourteen years. So I really sort of jumped straight into what I had to have done. You know, my treatment and that. I didn’t really have time to think about it really because I was working full time. I did long hours didn’t I Harry (speaking to her husband Harry)? I used to work in a library, and we used to work like 9 till half seven. But I've always been on the move. You know what I mean? Active, yep. So I didn't really have time. Anyway, when I went to Thameside it first was wasn't it? First time I had it. I just said to them...They said, you've got cancer. And I knew they were going to tell me that because there was always a nurse going in. I recognised the people that had cancer, there was always a nurse going in. So it was a give away. I knew, I knew before I got in so when I got in he said, it's cancer, you've got to have a mastectomy. I said fine, I just said fine, cos I'd already realised before I got in because, when I was going for a scan, I was looking at all the faces, and I could tell with the faces that there was a problem. Their faces changing. I always look at people's faces and I could tell. I knew straight away what I was going to be told. So I had a bit of time. And then I went back to the car, to sit in the car while I was waiting to see the consultant.

Step 3: Excerpt from the Final Restorying Draft of Rosemary's Narrative

No time to think

Well I've never had really time to think about things because I always worked long hours. I used to work in a library, and we used to work around nine till half seven. I've always been on the move and active, so I never used to sit around thinking. I got diagnosed with
cancer for the first time fourteen years ago now. And then it came back after fourteen years. So I really jumped straight into what I had to have done with my treatment without thinking that much about it.

When I went to the first hospital, the first time I had it, they told me straight that I had cancer. I knew they were going to tell me that because there was always a nurse going in and I recognised it was for the people that had cancer. So it was a give-away. I always look at people’s faces. So when I was going for a scan, I was looking at all the faces, and I could tell by looking at them that there was a problem. So at that time, it was a case of waiting to hear what I already knew and when the doctor told me I had to have a mastectomy, I just said fine. The fact that I already knew what I was going to hear gave me a bit of time, so I went back to sit in the car while I was waiting to see the consultant.
12th December 2012

Emily Cudworth
Haymount, Birgham,
Coldstream,
Berwickshire

Dear Ms Cudworth,

Re: Research Governance Approval for a narrative study

Study Title: Transformation of perceived female identity throughout cancer treatment: A narrative study [R&D/12/028]

Thank you for submitting your study to the Research Review Committee (RRC).

After reviewing the documentation for the above mentioned study I can confirm I have no objections for the study proceeding at The Christie Clinic.

Kind Regards,

[Signature]
Dr Arkenau
Medical Director

co Dr Clare Lennie (Clare.lennie@manchester.ac.uk)

An Affiliate of the Sarah Cannon Research Institute, USA
Sarah Cannon Research UK Limited Registered No. 7093837 England. Registered Office: 342 Moxleyhouse Road, London NW1 6HF.
Glossary

Avastin: A humanised monoclonal antibody used to treat colorectal, lung and kidney cancer.

BRCA Gene: BRCA1 and BRCA2 are abnormal genes that affect breast cancer in both men and women.

Chemotherapy: A cancer treatment that uses chemical substances. Most chemotherapy is administered intravenously, although a number of agents can be administered orally. When given intravenously, it is done so either on an inpatient or outpatient basis.

HER2 Positive: A breast cancer that tests positive for a protein called human epidermal growth factor receptor 2 (HER2), which promotes the growth of cancer cells.

Mammogram: An x-ray picture of the inside of the breast.

Metastasis: The development of secondary malignant growths at a distance from a primary site of cancer.

Radiotherapy: A cancer treatment that uses high-energy rays, usually x-rays or similar, to treat the disease.

Remission: A decrease in or disappearance of signs and symptoms of cancer. In partial remission, some, but not all, signs and symptoms of cancer have disappeared. In complete remission, all signs and symptoms of cancer have disappeared, although some cancer may still be in the body.

Tamoxifen: A synthetic drug used to treat breast cancer, by acting as an oestrogen antagonist.