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Professional Doctorate in Counselling Psychology (DPsych)

The View from Somewhere: A Personal and Professional Journey in Counselling Psychology

**City University, London
Department of Psychology**

Catherine Nelson

September 2010

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But this thesis has its roots in places other than the professional sphere. My mother helped me believe that you can follow your dreams, while my father's passionate advocacy taught me that some things are worth caring about. My sister- and parents-in-law, Frances, Connie and Bertie, showed me from their engagement with multiple cancers that, even at the worst of times, it is possible to live and love. Finally, through the many years of this mid-life career change, my husband and children have cheerfully accommodated my academic and clinical work into our lives. Their encouragement has meant more than they will ever know.

Section A: Preface

Life can only be understood backwards. But [...] it must be lived forwards.
(Kierkegaard, 1847, cited in Stevens, 1996: 185)

The work that forms this doctoral portfolio was not designed around a theme. On first viewing, a literature review on the use of gratitude within psychological therapy does not obviously link with a case study exploring the therapeutic relationship between client and counselling psychologist, nor indeed with a research study into changing identities following cancer. However, as I reached my final year of training I became aware that this work was intricately connected, through a multi-faceted exploration of meaning. As a woman changing career in mid-life, counselling psychology did not simply represent a qualification, but also a way of better understanding both my fellow human beings and my self. In his exploration of the philosophical underpinnings of existentialism, May (1983: 76) cites Nietzschean ideas which suggest that human beings should make "their experiences a matter of conscience for knowledge." The values and choices underlying the work in this portfolio form such a personal act of meaning: to paraphrase the American philosopher, Thomas Nagel, it is "the view from somewhere" (Nagel, 1986: 1).

In teasing apart this personal act, I hypothesise that there are three different ways in which I have sought to explore meaning. The first is through the decision to focus on material which is, in itself, concentrated on the understanding of meaning. Part of the interest in conducting a literature review on gratitude was the opportunity to consider how we appreciate – or endow with value or meaning – the different elements in our lives. As I discuss later, gratitude is a positive emotion which, by raising awareness of our good fortune or of others' concern for ourselves, can increase a person's sense of well-being. While we may be more used to considering gratitude within the sphere of everyday life rather than in the consulting room, research is now showing that interventions centred on the development of gratitude can increase wellbeing among the general population. Gratitude also appears to play a part in the adjustment of people who have experienced trauma, through cognitive

appraisals which attribute benefits to the self from traumatic event. Clearly, however, there are tricky ethical considerations about the way in which such discussions might arise; as Janoff-Bulman (1992) states, this understanding of trauma needs to arise from the client, rather than be imposed from the counselling psychologist. However, writing this literature review did indeed help me to appreciate benefits of gratitude, both for its therapeutic potential and for the greater understanding I gained about the people and things for which I was personally grateful.

The material of the professional work and the research study are very obviously connected with the making of meaning. In the case study, my client Abigail is seeking to make sense of the imminent death of her mother, within circumstances which significantly complicate the nature of this grief. The research project explores how, following an experience of breast cancer, younger women create meaning in their lives through continuity and change in their identities. As Frankl (1992) asserts, living through such circumstances is not a question of simple existence, but rather requires at some level a decision as to what existence will be. These studies take up questions of how meaning is constructed at the level of particular relationships or roles, but is also created through broader systems of personal belief and as well as the cultural discourses which shape our general approach and interaction with life.

Thus in considering the fundamental substance of this portfolio, I realised that I have been drawn to write about issues of meaning, through a desire to understand more about the nature of our existence as human beings and the way this existence is realised in our practical, everyday lives. However, there is also a second facet of meaning which is reflected throughout this portfolio, and this concerns efforts to understand professional meanings in my new identity as a trainee counselling psychologist. As Rose (1990) has argued, psychologists are not working within a fixed environment, but rather have an active role in the creation of this environment:

Psychology is not merely a space in which outside forces have been played out, a tool to be used by pre-given classes or interest groups. To the extent that its various theories have been more or less successful in enrolling allies [...] in producing calculable

transformations in the social world, in linking themselves into stable networks, they have established new possibilities for action and control. In establishing and consolidating such networks, in forcing others to move along particular channels of thinking and acting, psychologists have participated in the fabrication of contemporary reality. (Rose, 1990: 112).

During my first year of counselling psychology training, I worked within the National Health Service, and this clinical work involved treatment for a wide range of distress which could be coded as “psychopathology”. The choice to write a literature review on gratitude arose from my desire to consider how, instead of treating distress, psychological knowledge could be used to prevent such conditions occurring in the first place. In her “broaden and build” theory, Frederickson (1998) suggests that positive emotions undo the adverse physiological effects of negative emotions, and extend cognitive functioning through more creative, flexible or efficient patterns of thinking. This exploration of the potential of gratitude allowed me to conceive of a wider function for counselling psychology, which moved beyond the management of distress to a concern for alternative ways of promoting wellbeing. The resulting critical literature review was published in *Counselling Psychology Review* (Nelson, 2009), and has been updated here with relevant recent studies.

This interrogation of my identity as a counselling psychologist is also evident in my professional practice case study. While proficiency as a counselling psychologist clearly requires knowledge of appropriate therapeutic techniques, I had become increasingly interested during my final year of training in what is often called ‘use of self’: the degree to which the person of the counselling psychologist is, and should be, made manifest in the therapy room. Such issues of ‘being versus doing’ (Frankland & Walsh, 2009) involve consideration of the relative contributions of specific ‘methodological’ techniques and a psychologist’s empathic, accepting presence to a client’s progress in therapy. In writing this particular case study, I was attempting to make clear my growing sense of the two-person nature of psychological therapy, and my evolving conceptualisation of the psychologist’s role. This involved a shift from my earlier, more cautious work as a trainee, where I was more concerned with mastering the technical tools of the trade and less aware of working on the

messier and more complex relational issues which are so critical to therapeutic outcomes.

In choosing to explore the lived experience of women with breast cancer, I was again conscious of a choice motivated by my vision for counselling psychology. The substantial majority of studies concerning therapeutic interventions and cancer focus upon cognitive adaptation to this new state, and intra-personal factors relating to an individual's adjustment. However, while recognising the value of such research, my concern is that psychology restricts itself to the domain of the individual, and fails to understand how the meaning of cancer is actually transacted within the context of a person's daily life: our social world. Situating myself within critical realist framework, I hold that there is a material reality to our world – bodies, tumours, hair loss – but believe that our understanding is profoundly shaped by the ways in which we talk and act about these objects. Therefore the choice of methodology and research question in this study were, in some very small measure, a way of presenting an alternative understanding of the cancer experience within counselling psychology.

So in addition to an explicit focus on the types of meaning constructed, each piece of work within this portfolio represents my exploration of professional meanings available to a counselling psychologist. However, there is also a final facet of meaning which is present in my work, and which connects on an intimate level with the earlier levels of meaning. Following Bruner (1990), I perceive that my choice of perspectives in the pieces presented here represents my personal values and preferences. Such values, Bruner suggests, propose a basis for the satisfactory conduct of life, or at least a basis for negotiation: these values provide the foundation for self identity, as well as a means of locating oneself within a culture. This personal meaning is deeply present in each element of the portfolio. In choosing to write about gratitude, I was aware of wanting to resist the 'medicalisation' of counselling psychology. During my undergraduate studies, I was particularly inspired by the works of Csikszentmihalyi (1992) on the nature of "flow": a state when a person feels they are totally engrossed in and stimulated by an experience or activity. Thus I was attracted to exploring gratitude, and the new field of positive psychology,

because of the contrast it presented to my clinical work. As its founder, Martin Seligman (2003) describes, the intent behind positive psychology is to explore how to build wellbeing from a notional scale of 0 to +7, rather than the deficit reduction of clinical work which seeks to move the needle from -7 to 0. Clearly, the majority of work for counselling psychologists is in healthcare settings which require work within evidence-based models of care on the alleviation of distress. However, the increasing incidence of psychological distress within Western societies suggests that, as counselling psychologists and as human beings, we need to think more creatively about the ways of living which inform our lives. Positive psychology has been criticised as a kind of L-dopa for the masses; Barbara Ehrenreich (2009) is only one among many authors who has sought to challenge positive psychology for its 'unrealistic' focus on wellbeing, and for the emphasis it places on individual action rather than social change to achieve such ends. However, while accepting these criticisms, I have found positive psychology has offered me a way of appraising the ways of living which I offer to others through therapy, as well as the forms of working and living which I adopt in my own life.

In my case study, I was aware that an important personal meaning lies in the choice of therapeutic approach. I have a strong regard for the principles and utility of cognitive behavioural therapy (CBT), but have concerns that – as a counselling psychology trainee in the early twenty first century – the dominant focus on CBT is becoming something of a new "methodolatory" (Allport, 1937: 127). Understanding and shaping these cognitive and behavioural patterns has clearly enabled psychologists to find more constructive ways of living, and this is likely to be further enhanced in future through our greater appreciation of the neuroscientific composition of the brain. However, in a society which sees an increasing emphasis on technical aspects of self involving control over nature and the mind, I share the concern expressed by May (1983) that we are repressing our ontological sense of being. What excites me about person centred (and existential) therapeutic approaches is the embracing of these fundamental dilemmas of our human lives: our struggle with issues of non-being, which can be seen as both external, as in the reality of death, and also internal, as in the personal characteristics which limit us from fulfilling our own potentialities. Thus the choice to write my final case study within the person

centred model is partly an acknowledgement of the gratitude I feel for the inspiration and insight I have been able to draw from humanistic thinking during my counselling psychology training.

The research study contains perhaps the most personal meaning in this portfolio. At the beginning of my second year of post-graduate training, I was diagnosed with early stage breast cancer. As I describe later within a reflexive consideration during the research, I was deeply shocked by the diagnosis. Within in a week, it seemed that my whole world had been turned upside down. However, at the same time I have also been aware – both then and now – of my good fortune. This good fortune consisted not only of having family, friends and counselling psychology colleagues who supported me through this time, but also of having access to the resources of a profession which allowed me to make sense of my own experience. After a first year of training with personal therapy and reflexive journals, denying cancer didn't seem the way forward! The research study which I have developed here has therefore had very significant meaning for me, and while this is covered in more detail during the reflexive aspects of the research study, I would like to draw out two aspects of that meaning here. The first is that the research question arose in part from my own experience of cancer, where I found myself translating the meaning of cancer through the identities available to me in my everyday life. However, during investigation of existing research on cancer and identity, there was much less consideration of this area than I had expected, but rather a focus on the refinement of coping strategies and adjustment. As I shall discuss later, I believe a greater connection with the grounded, lived experience of cancer can enhance our capacity as counselling psychologists to support people in such situations.

The second meaning is both personal and public, or perhaps - as the early feminists advocated - the personal is the political. In her humane and thoughtful book about trauma, Janoff-Bulman (1992) discussed how those whose survival is threatened seek to rebuild their fundamental assumptions about the world. When the meaningfulness of the world appears to be overturned by an event, one typical response is to find new meaning by re-evaluating the disruptive event in terms of its benefits for self and others. In

going beyond my personal journal writings and conversations, I am aware that this research has provided me with an opportunity to explore the wider context of my own experience with cancer, and refine my understanding of personal 'lessons learnt'. However, I also know that another way of making sense of my experience was to use it in some way for the benefit of others. In his book "At the will of the body", Frank (1991) writes persuasively of the way in which medical and social systems deprive ill persons of conversations about their illness: their hopes and fears; their sense of suffering; the possibility of death. His image of health and illness as foreground and background strikes me as a critically important understanding; as counselling psychologists, we can do better work when we not only deal with the cognitive processing of our clients, but also deal in the detailed realities of managing an existence lived with cancer. Indeed, listening to these experiences of illness can help inform and develop particular Western definitions of 'health' as a controlled and disciplined body.

So while the elements of this portfolio may seem superficially un-connected, I can now look back and perceive how there are very material connections in the content of the work, and in the areas of personal and professional meaning. Frankl (1992: 104) has written movingly about his sense of the human "will to meaning": a primary motivational force in human beings to find meaning and sense in existence. He suggests that we can derive meaning in three ways: through creating work; through encountering someone; and through the attitude we take to unavoidable suffering. In re-reading Frankl's book, it struck me that in some modest way the literature review on gratitude, the case study about two-person therapy, and research into the experience of cancer can be related to each of these three different ways of finding meaning. The diversity of my work has made the years of training very challenging; both experientially and intellectually, I feel as if there has been considerable ground to cover. However, I now perceive that this challenge lies not merely in their status as assignments completed for the fulfilment of a portfolio. I now value these works as "acts of meaning" (Bruner, 1990: xii), whose purpose has been the greater understanding of my self and of my new profession of counselling psychology.

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Section B: Critical literature review

Appreciating gratitude:

**Can gratitude be used as a
psychological intervention to improve
individual wellbeing?**

Gratitude, as it were, is the moral memory of mankind.

(Simmel, 1950: 45)

1 Introduction

The value of gratitude has been frequently addressed in popular literature (Ryan, 1999; Miller, 1995). As Carman & Streng (1989) describe, gratitude is extolled as a fundamental virtue in all the world's major religions. People in most cultures appear to experience gratitude, and have developed their own linguistic and social patterns for its expression (Appadurai, 1989; Sommers & Kosmitzki, 1988). However, until recently, gratitude has received little attention within the psychological literature, and has been omitted from many major works on emotion (de Rivera, 1977; Lazarus, 1991).

But recently the nature and importance of gratitude has been reconsidered. In part, this traces to the growth of positive psychology. With a focus on developing improved wellbeing and optimal functioning, positive psychology has sought to develop "the scientific study of positive experiences and positive individual traits" (Duckworth, Steen, & Seligman, 2005: 630). As part of this scientific approach, Peterson and Seligman (2004) developed an inventory of twenty four character strengths, and the character strength of gratitude was one of the few which later associated most strongly with ratings of subjective wellbeing (Park, Peterson & Seligman, 2004). Alongside the development of positive psychology, an increasing range of new empirical research, together with a re-evaluation of older studies, has indicated that gratitude can improve well-being in two ways: directly, as a causal agent of wellbeing; and indirectly, as a means of buffering against negative states and emotions.

Greater understanding of the power of gratitude as a psychological intervention has wide-ranging significance for counselling psychology. Even at such an early stage, gratitude research can both inform individual strategies with clients and contribute to the development of more sustained programmes of intervention.

Gratitude research can amplify thinking within current theoretical models, including both cognitive behavioural and person-centred approaches. Finally, gratitude research can provide counselling psychology with ideas for interventions with a range of client groups, from those experiencing depression, bereavement or substance abuse, to individuals who are not experiencing clinical issues but are seeking simply to enhance their state of wellbeing.

In assessing the therapeutic use of gratitude to increase wellbeing, this review will cover three main areas. Firstly, it will provide an introduction to conceptualisations of gratitude and the place of gratitude within cognitive-emotional and biosocial theories. Secondly, it will examine a variety of research studies to evaluate evidence for gratitude's impact on individual well-being, both directly as a causal agent and indirectly as a buffer against negative states. Working within an evidence-based approach, this analysis will focus on empirical studies, although making use of psychoanalytical reports which may suggest future empirical research opportunities. Finally, this review will identify four main conclusions from existing gratitude research, considering implications both for theories of gratitude and for the practice of counselling psychology, as well as future research directions.

2 Conceptualisations of gratitude

Gratitude can be defined as "the quality or condition of being thankful; the appreciation of an inclination to return kindness" (OED, 1989). While gratitude has defied easy classification, most psychological research sites gratitude among the emotions. Gratitude has been acknowledged as a moderately pleasant and activating emotion (Mayer, Salovey, Gomberg-Kaufman & Blainey, 1991), with a distinctive cognitive form. It has therefore received attention from theorists studying cognitions as causes of people's emotional responses to events. Weiner, Russell and Lerman (1979) demonstrated that causal attribution and event valence predict the direction and magnitude of emotion, and from laboratory experiments suggested that the emotion of gratitude depends on appraisal of a positive outcome and on attribution of that outcome

to the efforts of others. Gratitude has also been conceived as one of the empathic emotions, dependent on the capacity to empathise with others (Lazarus & Lazarus, 1994). Within this conception, each emotion is seen as having a unique dramatic plot, with that of gratitude being appreciation of an altruistic gift.

However, this conception of gratitude has recently been expanded. More detailed analysis of studies involving gratitude has suggested that, in addition to appreciation of the helpful actions of others, gratitude may also arise from sources such as thankfulness for one's abilities, or for an environment which facilitated productive work. Thus, as Wood, Froh and Geraghty (in press) argue, the trait of gratitude is better seen as a wider life orientation towards noticing and appreciating the positive in the world. This general life orientation is supported by diverse and specific areas or facets of gratitude, including: appreciation of other people; a focus on, and thankfulness for, what the person has; feelings of awe when encountering beauty; focusing on the positive in the present moment; appreciation that life is short; and positive social comparisons. In a quantitative factor analysis of gratitude scales, Wood, Maltby, Stewart and Joseph (2008) found that these lower order facets form part of a higher order gratitude factor. Following Rosenberg (1998), Wood, Froh and Geraghty propose that people can be considered to have a strong orientation towards gratitude if they experience these lower order facets frequently, intensely and through a wide range of eliciting stimuli.

These conceptions begin to address an important question: what good is gratitude? Aside from the purely hedonic value of gratitude as a pleasant emotion, gratitude performs two important functions. Firstly, gratitude works at a societal level to stimulate pro-social behaviour. Simmel (1908/96) described gratitude as "the moral memory of mankind" (1908/96: 3), and Trivers (1971) and Bonnie and DeWaal (2004) have examined the potential adaptive and evolutionary benefits to a society rooted in gratitude. However, these moral functions of gratitude have been comprehensively documented elsewhere (e.g. McCullough, Kilpatrick, Emmons & Larson, 2001), and will not be considered here except where they add to understanding of well-being. Secondly, gratitude works at an individual level, to build lasting and beneficial

personal resources. In her “broaden and build” theory, Frederickson (1998, 2001) has suggested that positive emotions undo the adverse physiological effects of negative emotions, and extend cognitive functioning through more creative, flexible or efficient patterns of thinking. Thus over time, the broadening triggered by positive emotions builds a range of positive resources, which may help individuals transform themselves into more healthy, socially integrated and resilient people.

The potential of gratitude to build personal resources provides the link between gratitude and individual well-being. Subjective wellbeing is defined as “a person’s cognitive and affective evaluations of his or her life” (Diener, Lucas & Oishi, 2002: 63). In their research into a sustainable architecture of happiness, Lyubormirsky, Sheldon and Schkade (2005) have shown that interventions focussing on individual’s activities and practices can achieve lasting improvements in wellbeing. This review will consider to what extent gratitude interventions can improve wellbeing. Using the hierarchical levels of emotion proposed by Rosenberg (1998), most interventions described will focus on the development of a grateful mood: a sustained period of emotion which can vary across or within days. However, the review will also consider why future interventions by counselling psychologists might also be directed to furthering development of the trait of gratitude, which Rosenberg (1998: 249) viewed as a “more stable predisposition [...] towards certain types of emotional responding”.

3 Gratitude: A causal agent which improves individual wellbeing

3.1 General gratitude interventions

Several recent studies have employed rigorous and robust scientific methods to demonstrate the impact of gratitude on individual wellbeing, and to evaluate general gratitude interventions. Among the first was a comprehensive examination of the effect of grateful mood on psychological and physiological wellbeing by Emmons and McCullough (2003). This study was also an early pioneer of the ‘gratitude list’, which – as Wood, Froh and Geraghty (in press)

observe – has become the most researched gratitude intervention. In an initial study lasting ten weeks, participants (n=192) were asked to submit weekly reports documenting five things for which they were grateful, with further experimental conditions reporting on five hassles and five events. In subsequent Studies 2 (n=162) and 3 (n=65), several variables were investigated. A condition asking participants to focus on downward social comparison was substituted in Study 2 for a focus on hassles. Interventions were tested on both undergraduates (Studies 1 and 2) and adults with chronic illness (Study 3). Finally, the duration and frequency of interventions was manipulated, with the second and third studies requiring daily reports for two and three weeks respectively.

Across the studies, a wide range of benefits to wellbeing was reported. In Study 1, participants in the gratitude condition rated current and prospective life more favourably than the other two conditions; these participants also recorded fewer symptoms of physical illness and described spending significantly more time exercising. But despite these improvements in outlook and physical wellbeing, an important issue with this study was the failure of the gratitude condition to show increases in positive affect (PA). This situation changed in Studies 2 and 3, where the increased frequency of daily interventions appeared to affect PA. Study 2 produced significantly higher levels of positive affect (PA) than did the hassles condition, though differences in PA between the gratitude and events conditions were non-significant. In Study 3, in a straightforward comparison with a non-gratitude control, the gratitude intervention showed a significant increase in PA and decrease in negative affect (NA). Importantly, mediational analyses indicated that gratitude fully accounted for the effect of the gratitude intervention on PA, rather than PA mediating gratitude. Study 2 revealed no differences in reported physical health, potentially due to the significantly shorter time frame of the study. However, the gratitude condition here recorded more instances of pro-social behaviour, with these participants being more likely than those in the other two conditions to have offered emotional support to others. Study 3 also provided reassurance as to the validity of the self report measures of PA used in the earlier studies (see Schwartz & Strack, 1999), as significant effects of the gratitude intervention on wellbeing were also recorded by the participants'

partners. In summary, this extensive study provides important evidence as to the direct agency of gratitude in improving individual well-being. The randomised controlled trial (RCT) indicated these benefits were most obvious when compared to the hassles condition, but they were also recorded in direct comparison with a control condition. The benefits were achieved with only minimal intervention, requiring a few minutes of time each day or week. Replication of results across different participant groups also lends confidence to the generalisability of these gratitude interventions, while the qualification of differing intervention (daily vs weekly) frequencies and durations provides useful pointers for developing intervention schedules.

A second longitudinal study supports and extends the findings of Emmons and McCullough (2003), adding weight to the argument that gratitude interventions can directly increase individual wellbeing. Watkins et al (2003) carried out an experimental study to examine whether a different gratitude intervention - grateful reflection - could enhance PA, and how levels of PA might differ under a range of gratitude interventions. A RCT was used, with student participants (n=157) allocated to one of three gratitude conditions: thinking (reflecting on a living person for whom they were grateful); essay (writing about a living person for whom they were grateful); and letter (writing a letter addressed to a living person for whom they were grateful). All three gratitude conditions showed significant increases in PA compared with the control condition. However, the grateful thinking condition showed the strongest increase in PA, recording a mean change score in PA more than double that of the grateful letter condition. Other research may help to explain this finding. Lyubomirsky, Sousa and Dickerhoof (2006) found that writing and talking about positive events was associated with less PA than thinking about them, and hypothesised that this was due to processes of analysis and structuring inherent in writing, which may reduce the sense of pleasure and wonder inherent in positive emotional states. Watkins et al also found that scores on a measure of dispositional gratitude predicted affect changes in the gratitude experimental conditions. Individuals manifesting high trait gratitude showed stronger increases in PA than those with lower trait gratitude, though all recorded improved scores. Overall, research by Watkins et al provides further support from within a robust empirical setting for the effect of gratitude

interventions on wellbeing. Though the study is weakened by the restricted (student) participant base, and the lack of mediational analysis on the interaction of gratitude with PA, it does extend understanding of the range and potential of different gratitude interventions. Finally, though Watkins et al (2003) investigate more temporary changes in well-being than Emmons and McCullough (2003), their work supplies useful information as to the power of gratitude interventions among individuals with both low and high trait gratitude.

As well as underscoring the potential of gratitude to increase well-being, research by Seligman, Steen, Park and Peterson (2005) expands thinking on the efficacy and different interventions by examining the impact of grateful behaviours. This study involved a RCT of five happiness exercises among participants (n=411) recruited, briefed and evaluated via the internet. Two gratitude interventions were used. The first was a gratitude visit, which involved writing and delivering a letter to someone for whom participants were grateful. The second intervention involved "counting blessings" (another version of the previously mentioned gratitude list), by recording three good things every day. One strength of this study is the length of time over which interventions were evaluated, which led to insight on the impact of interventions. The gratitude visit produced the largest increase in happiness and decrease in depression during the first month of the study, but by month three, participants' affective states had returned to the baseline. The gratitude list intervention showed increased happiness and decreased depressive symptoms at six months. There are several considerations relating to the methodology and results of this study. Firstly, the participant group volunteered for participation through a positive psychology website, and thus their motivation to achieve increases in well-being may be higher than other groups within the wider population. This may be related to a second point. Seligman et al (2005) observed a significant effect within the gratitude list condition of participants' adherence to the gratitude intervention over time. In other words, participants' continued use of the intervention after the end of the test period contributed to the longer lasting effect of the intervention. This non-advised continuance provides support for the meaning and value of the interventions, suggesting that participants have 'voted with their feet' by

continuing the gratitude exercise, but this reaction might not extend to a more representative sample. Finally, the delivery of this intervention via the internet suggests that, for motivated individuals, this can be an effective and efficient method of providing psychological gratitude interventions.

Following this generally positive record of gratitude interventions, there is some evidence which provides a contrasting picture. Sheldon and Lyubomirsky (2006) ran a four-week experimental study to assess how the practice of two mental exercises might influence PA, and how this influence was mediated by motivation. Student participants were asked either to cultivate gratitude by counting things in their lives for which they were grateful, or to describe their best possible selves (BPS), visualising their ideal life in the future. Each group was then encouraged, but not required, to continue this exercise during the following two weeks. Results showed that only the BPS intervention produced a significant increase in immediate PA. The gratitude intervention fell midway between a control condition and the BPS exercise in terms of boosting PA, although it did not differ from either the BPS or the control condition. In addition, the BPS exercise produced the highest level of self concordant motivation, suggesting it evoked a stronger fit with participant's true values and interests. However, there are several aspects of this study which cause concern. At the baseline screen of participants, those within the gratitude condition recorded significantly higher negative affect than those in either of the other two conditions. The study's authors do not make clear whether current or previous experience of depression may have affected disproportionately those within the gratitude condition, and this could have been expected to affect adversely ongoing gratitude scores (e.g. Watkins et al, 2003). Moreover, the gratitude intervention involved outlining reasons for gratitude "in as much detail as you can", which as previously mentioned, may have resulted in the dissipation of positive emotion as reported by Lyubomirsky et al (2006). Contrasting this study with research conducted by Emmons and McCullough (2003) does suggest the importance of stipulating regular practice of a therapeutic intervention. It may be that certain interventions, such as those involving gratitude, involve more of a change in mental patterns than those requiring visualisation of BPS.

Concluding the review of general gratitude interventions, recent research also provides important insight as to how positive emotions such as gratitude can enhance well-being. Arguing that emotions have as much to do with the body as the brain, McCraty and Childre (2004) asserted that sincere positive emotions such as appreciation are associated with a higher degree of coherence in the heart's rhythmic activity, which they term "physiological coherence" (2004: 236). Further, McCraty, Atkinson, Tiller, Rein and Watkins (1995) reported that the extended human cardiovascular system works at its optimal resonant frequency when an individual is actively feeling appreciation or another positive emotion. In additional studies (McCraty, 2002; McCraty & Atkinson, 2003), a link was created between these physiological states and an increase in cognitive skills. Evaluated against a control group experiencing relaxation, an experimental condition experiencing the physiological correlates of gratitude showed significantly better performance in discrimination tasks requiring focussed attention, and in their ability to react quickly and accurately. There is one significant concern with this research to date, which is that it has largely focussed on appreciation, which is an aspect of gratitude but does not encompass the full range of feelings associated with gratitude, as defined earlier. However, these studies yield important findings as to the physiological processes which may underpin gratitude, and the ways in which positive physical and cognitive benefits can accrue from grateful moods. This work also suggests that interventions might explore not only grateful thinking, but also creation and mindfulness of grateful feelings, in order to achieve maximum increases in well-being.

3.2 Gratitude and psychotherapeutic interventions

Gratitude interventions have also been used as part of wider psychotherapy programmes targeting individuals with clinical issues. Seligman, Rashid and Parks (2006) developed a programme of positive psychotherapy (PPT), where two of the twelve sessions focussed on gratitude-related interventions. This PPT was delivered in group sessions to individuals diagnosed with mild-moderate depression (n=40). A modified programme, divided into roughly equal sessions of traditional CBT treatment for depression and PPT, was delivered via individual therapy to individuals diagnosed with unipolar

depression (n=46). For the purposes of this review, a key weakness of this study is the inability to evaluate the contribution of specific gratitude interventions on results. However, the results of the overall programme are significant, and suggest the potential for counselling psychologists in trialling programmes of therapy which mix traditional CBT approaches with aspects of positive psychology such as gratitude. For those participants with mild-moderate depression, six weeks of group PPT resulted in significant improvements in depressive symptoms and life satisfaction at one year. Individual CBT/PPT therapy for unipolar depression recorded more symptomatic improvement and more remission from depressive disorders than treatment as usual, and than treatment as usual plus anti-depressant medication. There are several potential limitations to this research. The studies were conducted exclusively among students, and sample sizes, although not unusual for psychotherapy research, were smaller than many empirical psychology experiments. Finally, failure to rotate therapists meant there may have been a therapist effect.

Two recent studies have also explored how gratitude lists may be as effective as techniques commonly used in clinical therapy. The first study by Geraghty, Wood and Hyland (in press) was conducted among a sample of people (n=479) with severely impaired body image. Participants were allocated to one of three conditions: a waiting list; a gratitude condition, which involved keeping daily lists of things for which the client was grateful; and a daily automatic thought record (ATR), where negative thinking about body image was both documented and challenged. Among those completing the study, both the gratitude and ATR groups recorded a significant decrease in body dissatisfaction compared with the waiting list, suggesting that the gratitude list is at least as effective as a current standard clinical technique. However, it is notable that the gratitude group was more than twice as likely to complete the intervention, compared with participants completing the ATR.

Similar results were found in a second study by Geraghty, Wood and Hyland (2010), among people who exhibited excessive worrying (n=247). Under implementation of the same conditions, the gratitude condition again recorded reduced levels of worry equal to the ATR group, with both conditions being

significantly lower than the waiting list control. People in the gratitude condition were again found to be more likely to complete the intervention than those in the ATR group. The authors suggest that anecdotal evidence implies that participants found the gratitude diaries more enjoyable, and propose that this option may be particularly useful where compliance is likely to be an issue. Taken together, these two new studies provide encouraging evidence about the potential of gratitude interventions to improve wellbeing for those with clinical issues. Further work is required to confirm and extend the findings from these studies, both among different clinical populations and with different interventions.

4 Gratitude: A buffer against negative states and a stimulus for growth

Evidence presented so far has indicated that gratitude interventions can directly increase wellbeing. However, gratitude also appears to play an important role in buffering against negative states and in promoting growth through trauma. To understand better this role, it is helpful to begin with a brief review of the personality correlates of individuals who exhibit high trait gratitude. While such cross-sectional studies do not provide evidence for the active role of gratitude, they supply useful information on links between gratitude and increased resilience to negative states or situations.

McCullough, Emmons and Tsang (2002) provided the first extensive analysis of the grateful disposition. In research which generalised across both students and a large sample of adults (N=1266), they reported that self ratings of high dispositional gratitude correlated significantly with many measures of positive emotionality and well-being, including vitality, hope, optimism, happiness, lack of depressive symptoms and lack of anxiety. High dispositional gratitude was associated among adults with being spiritually minded and being more forgiving when hurt by others. Importantly, this research also controlled for the effects of Big Five personality variables such as Extraversion as well as for the influence of general positive affect, and found that gratitude accounted for variance in nearly all the measures of well-being. Watkins et al (2003) carried

out a similar correlational study among students. Again, a strong relationship was found between high dispositional gratitude and high levels of PA and life satisfaction. Depression, as measured by the Beck Depression Inventory, was found to have a strong and reliable inverse correlation with dispositional gratitude. A grateful disposition was also shown to have a strong negative correlation with narcissism, and an inverse correlation with anger.

Understanding links between dispositional gratitude and other emotions helps explain the role of gratitude interventions in reducing negative states. For example, Baron (1984) conducted an experimental study which involved assessing the potential of gratitude to reduce destructive conflict. Following theories that people are incapable of engaging in two incompatible responses at once, results showed that individuals exposed to a gratitude intervention after conflict displayed more positive ratings of their opponent, as well as reporting a significantly higher preference for constructive modes of dealing with the conflict (e.g. collaboration vs avoidance). One issue with this study is that feelings of gratitude are inferred following receipt of a gift, but not directly assessed. However, if grateful moods contain similar emotional contingencies to dispositional gratitude, the study can be argued to receive practical support from the study by Watkins et al (2003) cited earlier, where anger is inversely correlated with gratitude. Moreover, Nussbaum (1994) provides theoretical support for the power of gratitude to “undo” the negative emotion of anger. She describes how gratitude and anger have similar, but opposite, structures: I am grateful to [S] for [X], rather than I am angry with [S] for [X]. It is possible to hypothesise that a similar oppositional relationship may exist between gratitude and other negative states, such as materialism. Kasser (2002) cited several studies where materialistic values have been associated with a variety of problems in personal wellbeing, including depression, anxiety and narcissism. Research into dispositional gratitude (McCullough et al, 2003; Watkins et al, 2003) shows that it is uniformly negatively correlated with measures of materialism and envy. Adler and Fagley (2005, cited in Polak & McCullough, 2006) suggest that gratitude may counteract materialist strivings and their negative effects by tapping into an ability to appreciate what we have in life, which they find strongly related to subjective wellbeing. Unfortunately, there is currently no empirical work to support these claims.

So it can be argued that gratitude plays a role in buffering against negative emotions such as anger and the adverse effects of materialism. Research also suggests that this role extends to protecting individuals against the development of psychiatric illness. Kendler et al (2003) examined the relationship of dimensions of religiosity to lifetime psychiatric and substance abuse disorders. Gratitude was represented by a measure named Thankfulness, which encompassed feelings of gratitude as opposed to ingratitude, as well as a sense of thankfulness rather than anger towards life and God. Thankfulness was one of only two dimensions which was associated with reduced risk for both internalising disorders (major depression, phobias, panic disorder, bulimia) and externalising disorders (nicotine and alcohol dependency, drug abuse, adult anti-social behaviour). Again, this research is cross-sectional and not longitudinal, and so it cannot examine causal relationships. However, negative correlations cited earlier between dispositional gratitude and depression (e.g. Watkins et al, 2003) help support the idea of gratitude as a protective trait. Furthermore, there is evidence from small-scale therapeutic work in Japan that gratitude interventions can improve well-being for those experiencing anorexia and alcoholism (Morishita, 2000; Suwaki, 1985). Sakuta, Shiratsuchi, Kimura and Abe (1997) described how this Naikan therapy cultivated an appreciation of the contributions of others to the individual undergoing therapy, and how such interventions resulted in a sense of gratitude and in improvement of symptoms.

Moving on from an examination of negative states, research indicates that gratitude can be used as coping strategy to increase well-being during times of stress or adversity. In her phenomenological study of survivors of Hurricane Andrew, Coffman (1996) found that thankfulness for the safety of homes or families was the first of seven themes to emerge in individuals' accounts following the disaster. Similarly, research by Ventura and Boss (1983) indicated gratitude was the basis for one of three coping patterns adopted by parents after the birth of a child ("telling myself I have many things to be thankful for"). Kashdan, Uswatte and Julian (2006) found dispositional gratitude to show an inverse correlation with post-traumatic stress disorder in veterans; additionally, for both PTSD and non-PTSD groups, ongoing daily experience of

gratitude was associated with better daily functioning, irrespective of level of symptoms. In their research into benefit finding in adversity, Tennen and Affleck (2005) provide clues as to how gratitude may enable individuals to cope. Bowers et al (1998, cited in Tennen and Affleck, 2005) reported that among bereaved HIV sero-positive men, greater appreciation of loved ones and a perception that life was precious was associated with multiple effects. It correlated with both increased self-understanding and enhanced interpersonal functioning, and benefit-finding also anticipated slower HIV progression and was associated with a lower rate of AIDS-related mortality in the next four to nine years. These results have greater validity due to mediational analysis, which showed that disease progression was not mediated by health variables but fully accounted for by appreciation of benefits. These studies provide important understanding as to how participants use gratitude, consciously or sub-consciously, to improve well-being in times of adversity. However, to date there appear to have been no studies examining psychologists' use of gratitude as an intervention in such situations.

A similar absence of longitudinal, mediational research exists when reviewing evidence for the potential of gratitude to facilitate personal growth through crisis. Frankl (1962) proposed that people seek to create new life meanings as a way of defeating feelings of loss and despair. Drawing on a variety of qualitative and quantitative research, Nolen-Hoeksema and Davis (2005) describe how loss can lead to developmental change by confronting people with new situations and issues, and that types of growth in such situations show remarkable consistency across a wide range of traumas. One of the three main types of growth cited by Nolen-Hoeksema and Davis (2005) is growth in relationships, resulting from increased appreciation of significant others and a reduced focus on everyday problems. It is worth noting that the role and power of gratitude may have been underplayed in trauma literature to date. Previous research has found dispositional optimism to be the strongest and most consistent predictor of benefit-finding (Affleck and Tennen, 1996; Davis, Nolen-Hoeksema and Larson, 1998), but this research pre-dated the development of a reliable measure of dispositional gratitude. Moreover, recent work has provided indirect but compelling evidence of the role gratitude plays in transforming the lives of highly generative individuals. McAdams, Diamond,

de St Aubin and Mansfield (1997) described how highly generative adults tend to construct life stories around what they call a "commitment story". This commitment story can be seen as a "narrative of thanksgiving" for the redemptive move in their story, which allowed them to recover from earlier adversity. Moreover, McAdams and Bauer (2004) describe how even the concept of generativity can be seen as an offshoot of gratitude, inspired by a desire to give something back. Thus there appear to be several studies which indicate that gratitude plays an important role in enabling growth through crisis, but no research which has explicitly examined causative links, or evaluated specific interventions.

Indeed, opinion has differed over the power and role of psychological interventions for people experiencing difficult times. Tennen and Affleck (1999) described how even well-intentioned efforts to encourage benefit-finding have been perceived as insensitive and inept, and viewed as an unwelcome attempt to minimise the burdens and challenges that needed to be overcome. However, Nolen-Hoeksema and Davis (2005) suggested that, within a person-centred model which presupposes non-judgmental listening and recognition of the uniqueness of an individual's experience, supportive interventions might highlight growth in character and skills. From their research, they recommended what might be termed "indirect" gratitude interventions, such as asking a bereaved person about changes in perspective as a result of loss, or starting a discussion as to the ways in which trauma may have contributed to new ways of functioning. These interventions, which may fit with more experiential person-centred approaches such as that outlined by Rennie (1998), have also received further support from research from Wood, Linley, Maltby, Baliousis and Joseph (2008). Wood et al. showed that gratitude had important links with the Rogerian concept of congruence; specifically, gratitude was strongly and positively correlated with authentic living, which involved behaving in ways consistent with personal beliefs and values, while gratitude was negatively correlated with self-alienation, which was described as having inaccurate symbolisation of experience, inconsistent beliefs and a weak sense of identity. Thus it appears that, within the emerging literature on gratitude, there may be important connections with person-centred practice, in addition to those with cognitive practice outlined earlier.

5 Discussion

5.1 Conclusions

Having considered relevant literature, it is time to form an answer to the research question: can gratitude be used as a psychological intervention to improve individual wellbeing? Despite its short research history, it is already clear that gratitude can play an important role in enhancing individual wellbeing. Drawing together both theoretical insights and practical learnings, this section aims to establish four substantial conclusions from research previously discussed. By embracing these conclusions, and helping lead further research, counselling psychology can develop work within therapeutic models such as CBT and person-centred counselling, and extend its practice across a range of client groups and clinical disorders.

The first conclusion is that interventions which develop individuals' grateful mood can directly increase individual wellbeing. This causal link has been reliably demonstrated in several robust longitudinal studies, which have included mediational analyses (Emmons & McCullough, 2003) and non-self report measures (Watkins et al, 2003). The validity of these findings is further enhanced by the generalisability seen to date across differing participant groups, from students to motivated adults and adults with chronic illness as well as clinical issues such as body image or anxiety. Thus such research supports theoretical ideas about a sustainable architecture of happiness cited at the start of this review. Following Lyubomirsky et al (2005), it appears that despite individuals' dispositional levels of happiness and circumstantial situation, interventions which focus on changing a person's activities and practices can achieve lasting improvements in wellbeing. The findings also add weight to the "broaden and build" theory of positive emotions (Frederickson, 1998; 2001). Similar to other positive emotions, gratitude appears to have its own pattern of positive benefits, which include reduced depressive symptoms (Seligman et al, 2005), strengthened relations with others (Emmons & McCullough, 2003), and enhanced physiological and cognitive functioning (McCarty & Atkinson, 2003). Therefore, as with other positive emotions,

gratitude can be seen both to improve immediate capabilities and also to develop practical and psychological resources for potential future use.

This has significant implications for counselling psychology. For example, while the vast majority of work within cognitive behavioural therapy focuses on analysis and removal of negative states, perhaps an equally valid route might involve the strengthening of positive states. Indeed, Duckworth et al (2005) have suggested that positive experiences or traits are not necessarily slave processes to some negative state or trait. Thus a "build what's strong" approach may usefully supplement (or eventually replace?) the traditional "fix what's wrong" strategies. Positive results from individual interventions and from programmes such as PPT (Geraghty et al, 2010; Seligman et al, 2006) is encouraging. Such initiatives now need to be refined and qualified on a larger scale.

A second conclusion from this literature review is that, while there is greater understanding as to how interventions can create grateful moods, little knowledge exists as to how interventions can help create grateful dispositions. Most empirical research on gratitude interventions to date has focussed on examining the longitudinal effect of mood on wellbeing. In those few instances where gratitude interventions have been examined over a longer time scale (e.g. Seligman et al, 2005), there has been no assessment as to how or whether continuous evocation of grateful moods evolves into the more substantial emotional disposition described by Rosenberg (1998). From a developmental perspective, isolated studies have examined children's comprehension and expression of gratitude (e.g. Gleason & Weintraub, 1978), but no sustained research has been conducted on the emergence of gratitude in children. This is a critical omission, as analysis from a number of studies (McCullough et al, 2003; Watkins et al, 2003) shows robust correlations between a grateful disposition and many desirable states such as happiness, life satisfaction, as well as inverse negative correlations with depressive and anxious symptoms, narcissism and anger. What is lacking is theoretical knowledge as to how the grateful disposition develops, and evaluation of counselling psychology and social interventions which could encourage it. Existing research suggests that, while distinct from all Big Five Personality

Variables, gratitude shows most overlap with Agreeableness (e.g. Saucier & Greenberg, 1998). Since meta-analysis of traits estimates Agreeableness to have a heritability of 0.28 (Loehlin, 1992, cited in Cloninger, 1996), it seems possible that interventions directed at early environments, carers, family life and upbringing regimes can have a significant impact on the development of a grateful disposition.

A third conclusion, concerning the potential of gratitude interventions to buffer against negative emotions, can at this stage only be regarded as tentative. Existing longitudinal research into the effect of gratitude on anger is encouraging (Baron, 1984), as is initial evidence as to the negative correlation between gratitude and materialism (McCullough et al, 2003; Watkins et al, 2003). However, greater theoretical understanding is needed about the cognitive and affective mechanisms by which a positive emotion can buffer against a negative affect. Furthermore, there is a need for substantial, longitudinal studies in this area, to measure clearly the unique agency of gratitude hinted at in earlier studies.

Moving on to the final conclusion, evidence is compelling for gratitude's indirect role in promoting coping and growth through adversity. A range of studies using different quantitative and qualitative methodologies (e.g. Bower et al, 1998; Davis et al, 1998; Kashdan et al, 1996; Ventura & Boss, 1983;) suggest that gratitude and appreciation of benefits can enable individuals to cope with diverse situations including bereavement, natural disasters and health problems. Gratitude may also be a significant factor promoting personal growth and relational well-being (McAdams et al, 1997; Tsang, 2006). However, while there are some causal and many associational links between gratitude and well-being in these areas, there is little direct evidence of particular psychological interventions which have promoted such wellbeing. Indeed, within the person-centred models of counselling frequently used in bereavement and crisis counselling, the idea of direct gratitude "interventions" is theoretically incompatible. The role and form of gratitude interventions in this area is a matter which counselling psychology could usefully explore.

5.2 Directions for future research

Despite positive early findings on the causal link between gratitude interventions and individual wellbeing, considerable further research is required. On a conceptual level, the recent analysis from Wood et al (in press) provides a better understanding about both the structure and content of the trait of gratitude. This helps clarify how early studies with apparently different aims – the investigation of thankfulness to others, a focus on the present – can be related to a broader overall phenomenon. However, this new conceptualisation also appears to ask for some re-working of the existing literature, so that psychologists can assess whether there are particular facets of gratitude which are more powerful than others. Moreover, in future studies, psychologists need to be mindful of the specific facets of gratitude which are being assessed in their research.

For counselling psychologists, one key area requiring investigation is the optimal delivery of interventions which create grateful moods. Current research suggests that even brief, five minute exercises carried out consistently result in improvements in wellbeing, but might activities with longer duration, greater daily frequency or a biweekly “big bang” intervention (c.f. Seligman et al, 2005) lead to improved results? Consistency of practice appears to have been a factor behind the failure of one gratitude intervention (Sheldon and Lyubomirsky, 2006). Building on knowledge about importance of self-concordant motivation to achievement of goals (e.g. Sheldon & Houser-Marko, 2001), future qualitative research might consider how to boost motivation in such interventions, or how to address major obstacles preventing the regular use of gratitude tools. Further work is required to identify the relative power of different gratitude interventions. While a small number of interventions has already been proven successful, ranging from lists of three good things (Emmons & McCullough, 2003) to thinking or writing to someone to whom one is grateful (Watkins et al, 2003), ongoing research might seek to develop still more powerful alternatives, or to understand how currently available options can best be tailored to the needs of different client groups. Finally, in this evaluation of gratitude interventions, future research needs to be more attentive to the structuring of control groups. As Wood et al argue (in press),

understanding of active factors within interventions can be better understood through control groups where variables are closely and gradually varied, rather than with very differing practices.

What research routes might counselling psychology explore, to understand better the developmental factors and counselling interventions which can affect the grateful disposition? One possible path may be to explore clinical insights from psychoanalysis, where Klein (1957/1997) has suggested that the loving nature of a child's early relationships with his or her mother develops the alternate capacities for gratitude or envy. Another idea might be to examine the influence of particular environmental factors such as religion on the grateful disposition. Intrinsic spiritual beliefs have been shown to have strong associations with dispositional gratitude (McCullough et al, 2002), and future research might examine what previous environmental factors (aspects of religious practice, family or community spiritual beliefs) might be linked to these beliefs. Finally, once the developmental trajectory of the grateful disposition is better understood, it may be productive for counselling psychologists to consider incorporating such learnings into long term, preventative community programmes. If future research strengthens early findings that grateful mood and a grateful disposition can protect individuals from mental health issues, the dimensional distribution of mental health issues within a country would argue for a population approach (Huppert, 2004), potentially delivered as part of proven parenting or school programmes such as the Triple P (Sanders, 1999) or the Penn Resiliency Programme (Freres, Gillham, Reivich & Shatte, 2002).

Counselling psychology can play a significant role in qualifying how gratitude interventions may help buffer against negative states, or promote coping and growth through adversity. To ensure environmental validity, these studies would ideally be conducted within real-life settings, and with a range of client groups such as adults within the workplace or individuals referred with issues such as anger management. A first step may be detailed theoretical and practical studies into the ways in which gratitude builds wellbeing through adversity, for example through increasing appreciation of simple pleasures, changing values attributed to different elements of human lives or through

awareness of new and valuable skills acquired in adversity. Research could also expand on ideas from Nolen-Hoeksema and Davis (2005). Counselling psychologists could examine “indirect” gratitude interventions such as focussing on changes in perspective or new ways of functioning, and consider how these might fit conceptually with less directive forms of counselling. Finally, given recent development of reliable measures for assessing dispositional gratitude, it will be important to understand to what extent dispositional gratitude is correlated with coping and growth in adversity, and whether those with high and low trait gratitude need different counselling interventions to enable them to cope with trauma.

Finally, a programme of qualitative research could significantly extend understanding of the impact of gratitude interventions. To establish the value of gratitude to psychological study within an empirically dominated research establishment, most recent studies have sought to achieve quantitative demonstrations of causal links between gratitude and wellbeing. However, now that the value of gratitude is becoming more widely recognised, a multi-disciplinary programme of qualitative and quantitative study may lead to faster progress in understanding. One avenue of enquiry might be to explore how the experience of different interventions such as grateful thinking or a grateful letter is associated with different meanings for individuals. Other research could consider how cross cultural factors affect the experience of gratitude, and therefore the development of interventions. Finally, qualitative studies could explore people’s experiences of social messages and expectations concerning self-sufficiency or wealth creation, and how these might conflict with the development of gratitude. Possible ways of addressing these barriers could also be explored.

6 Summary

Despite the short history of gratitude research, there is already exciting evidence that gratitude can be used as a psychological intervention to improve individual wellbeing. Such findings are providing increased impetus to the ongoing study of gratitude, and to the field of positive psychology generally.

This paper has sought to show that the potential of gratitude interventions has wide-ranging relevance to counselling psychologists working across diverse client groups and within different theoretical models. In the words of Dietrich Bonhoeffer (1967):

In ordinary life, we hardly realise that we receive a great deal more than we give, and that it is only with gratitude that life becomes rich. (1967: 370).

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Section C: Professional case study

Person-centred or two person-centred therapy?

Exploring the meaning of the therapeutic relationship in person-centred therapy.

...but I too have met the tribal will to impose
taboos and codes, and have behaved rudely,
invoking my dead wife in dinner-table conversation.
A beat of silence, of shared fear and sick shock, falls,
a symptom of the malaise that James himself calls
“the awful doom of general dishumanisation.”

(Reid, 2009: 47)

1 Introduction

At the end of my training in counselling psychology, my work with Abigail¹ emerged for many reasons as the obvious candidate for this study. On a clinical level, Abigail was seeking to make sense of the imminent death of her mother, within circumstances which hugely complicated her grief. Our work together indicates the benefits which a person-centred approach can offer in a bereavement context, and makes links on this clinical level with the search for meaning in other aspects of my doctoral portfolio. On a theoretical level, my growing psychotherapeutic experience has led me to acknowledge the significance and potential of the use of self. This case confirmed for me that person-centred therapy does not mean the provision of certain conditions, but rather the offer of a two-person relationship – an encounter – where the psychologist aims to embody attitudes which facilitate growth. Finally, in addition to its significance on clinical and theoretical levels, my work with Abigail asked me to assess my competence in offering such an encounter. Throughout this study, and with the assistance of personal reflection and supervision, I hope to illustrate my capacity to create this depth of therapeutic relationship, while highlighting areas of growth for the future.

¹ Names and certain personal details have been changed to ensure confidentiality of client information.

2 Theoretical orientation

2.1 Person-centred theory

According to person-centred theory, psychological distress arises when an individual's self-beliefs conflict with their experiencing. Rogers (1959) argued that these beliefs - conditions of worth – were introjected from relationships with others. Discrepancy or incongruence between beliefs and experience, and thus the psychological distress, could be resolved through a therapeutic relationship which followed six conditions: psychological contact between two persons; a client who is in a state of incongruence; a therapist who is congruent or genuine in the relationship, and can experience and communicate both empathy and acceptance to the client. Rogers argued this relationship was sufficient for change to occur, as the therapeutic conditions facilitated a person's innate tendency for growth and thus greater congruence between beliefs and experience.

Recently, person-centred practitioners have debated the form and significance of this relationship. Some, such as Sanders (2007), work from a position which sees change as occurring within the individual, amidst a climate created by the therapist. Others such as Schmid (2007:37) argue that change occurs through a co-created process, where "the actualising tendency as a force of individual is embedded in the interconnectedness or social nature of the person". Considering relational depth, a heightened form of this two-person relating, Mearns and Cooper (2005: xii) propose that this "state of profound contact and engagement between two people ... [occurs when] each person is fully real with the Other, and able to understand and value the Other's experiences at a high level".

My practice as a trainee counselling psychologist has been influenced by relational approaches, and also by the experiential tradition described by Rennie (1998). This respects the fundamental person-centred principles of client autonomy and working from within the client's world; however, it also emphasises how growth occurs through the self-awareness and agency enabled by reflexivity. If a client is in a state of non-reflexive emotional

distress, “the therapist may expedite the progress of therapy by being directive about the client’s processing of experience” (Rennie, 1998: 9), although such interventions must be carefully raised to ensure they are acceptable to the client.

2.2 Bereavement theory

Earlier models for bereavement work envisaged clients moving through a series of stages (Kubler-Ross, 2009) or tasks (Worden, 1983). Latterly, Stroebe and Schut (1999) proposed a dual process model, suggesting that productive grief work involves an oscillation between two aspects: a loss orientation, where the client is addressing issues relating to the death of another; and a restoration-orientation, where the client explores the wider life changes required as a result of the death. Through this dual process, individuals develop new meanings which enable them to adapt to their changed world.

3 Context and referral

3.1 Biographical details

Abigail was a Caucasian woman in her early thirties. Her physical appearance was neat and casually smart. From the first meeting, Abigail generally sat still in her chair and maintained regular eye contact, in a way that suggested a purpose and commitment to her presence.

3.2 Referral and presenting problem

In my work at a cancer centre, Abigail was referred to me following her request for a one-to-one meeting with the psychology team. Abigail stated that she was experiencing significant distress, in the form of intense numbness, broken sleep and low mood. Abigail’s mother had recently been diagnosed with terminal cancer. Abigail described the relationship with her mother as especially close, “like a best friend”, in part due to her childhood circumstances. Until the time Abigail was eleven, Abigail and her mother had

experienced regular physical abuse from Abigail's father. After her parents' divorce and her father's disappearance from their lives, Abigail mentioned supporting her mother emotionally and practically, such as with the care of her much younger brother. She had experienced depression while at university, and mentioned that counselling had not helped.

Abigail also described major concerns with her marriage and her work. To care for her mother, she had returned from America where she and her husband had been working. This distance was now adding to earlier doubts about the value of both her career and her marriage.

3.3 Initial assessment

Opinion is strongly divided within person-centred approaches as to the appropriateness and utility of assessment. Sanders (2006), following Rogers (1951), argued that formal assessment and diagnosis do not fit with person-centred values. Such a medicalised process requires a judgement of the client's state which goes against respect for the client's authority, and has limited value as understanding of issues evolves throughout therapy. However, Wilkins and Gill (2003) challenge this view, suggesting assessment within a medical setting can respect client autonomy, provided it is collaboratively and sensitively handled. This perspective informed my work during an initial assessment session with Abigail, where I sought to respect her authority through mutual consideration of appropriate support.

Research into bereavement outcomes by Parkes (2006) and Stroebe, Schut and Stroebe (2007) indicates psychological support should not be routinely offered to bereaved people, but targeted at those experiencing complicated grief. Such grief arises from situational issues (e.g. type of lost relationship, ongoing conflicts), intrapersonal factors (e.g. pre-bereavement depression and previous losses) and interpersonal factors (e.g. social support), and is significantly less likely to be resolved spontaneously. Stroebe et al reported that – unlike bereavement work among the general population – psychological interventions in this area have been shown significantly to improve client's wellbeing. Multiple studies (Currier, Holland & Neimeyer, in press; Schut,

Stroebe, van den Bout & Terheggen, 2001) indicate person-centred therapy is effective in helping resolve such issues of grief.

In our initial assessment meeting, discussion of Abigail's situation led us to recognise the complicated grief she was experiencing. We explored the possibility of depression, but decided this was not currently an appropriate descriptor, due to the absence of full DSM symptoms (DSM-IV, 2000) together with Abigail's own sense of her experience. Abigail stated a strong preference for explorative therapy which allowed her to understand and express the emotions she was experiencing. I therefore felt our decision to start person-centred therapy was fully congruent with Abigail's and my knowledge of her preferences, and with clinical evidence.

3.4 Contract and plan for psychological counselling

Bordin (1979) proposed that establishment of clear tasks and goals, and the nature of the bond between psychologist and client, are critical to success in any therapeutic relationship. Rogers (in Baldwin, 2000) described how the person-centred therapeutic goal is process; here, our initial contract was to identify and explore the sources of the numbness and difficult emotions which Abigail experienced. In terms of task, Abigail and I agreed to meet weekly, with a formal review of progress every six sessions; we would discuss whatever emotional material Abigail felt important in that week. Considering our bond, I sought feedback concerning those aspects of her previous therapy which had been unhelpful. Abigail mentioned feeling no connection with her earlier therapist, whom she felt had used "psych-speak" and bald questions about how she was feeling. While she said that she instinctively felt positive about our relationship, we agreed I could regularly check on these issues.

4 Initial phase of therapy

In reviewing this case, I have chosen to combine case history and process reflections. In line with Rogers's observation above, the two are inextricably combined, and this approach allows me to show the inter-connections. I have

however divided the case/process history into three parts: issues in early sessions; significant developments in session six; progression and conclusion of therapy. This decision is borne out of the substance of therapy, where session six formed a pivotal moment in our work.

4.1 Key content & process issues in early sessions

From our second session, a number of patterns became evident in Abigail's construing of her experience. Talking of the numbness she felt about her mother's condition, Abigail described herself as being in "survival mode", which meant "being hard": blocking out negative feelings which might be overwhelming or terrifying, and trusting in only a handful of people. In response to my invitation to elaborate, Abigail indicated how "being hard" had been an essential survival strategy or condition of worth when she was growing up. Spontaneously, she described how, at the age of ten, her mother had been locked out by her father, who was ignoring the banging at the door. Hoping her father was too drunk to notice, she had subdued her fear and crept down to open the door. However, her father heard her and began beating her in the doorway, whereupon her mother smashed the door's glass panel to turn the handle and help Abigail. When I shared my sense of great sadness for the ten year old Abigail, and the horror she had to cope with, Abigail replied that she felt she had to block out her feelings to avoid provoking her father or further distressing her mother.

This interchange intimated something of the potential for relational depth. Working from a two-person conception of therapy suggested by Mearns and Cooper (2005), I had sought to offer an invitation for Abigail to meet me in exploring her feelings at a deeper level. Yet Mearns and Cooper also propose that such a meeting requires willingness from the client in sharing the most vulnerable and frightening aspects of themselves, as Abigail did here. Abigail's disclosure touched me profoundly, and while my response aimed to indicate my empathy and prizing of both the 'child' and 'adult' Abigail, I feel my comments were also a congruent statement of my feelings as a real person, rather than what Rogers (2007) termed a professional façade. Abigail received my comments quietly, appearing to have tears in her eyes. Noting this, and

mindful of our initial conversations about the alliance, I sat with her in the silence, before reflecting that I would trust her to tell me if, at any time, she did not want to talk. Abigail affirmed that she would.

During sessions three to five, we explored the condition of “being hard” more extensively, while creating understanding of another condition: being helpful. Abigail described how she felt appreciated and loved when she was able to support others. She reflected how, as a child, she was aware of being valued by her mother for taking care of her brother, and how this had extended as an adult to ongoing support for her brother, as well as a mediating role in the difficult relationship between her mother and brother. In explaining this, Abigail began to explore how this condition of “being helpful” had made it harder for her to assert her own need for support, and had in some ways reinforced the first condition of “being hard” and denying her emotions. Although an expression of love, we considered how managing the palliative care of her mother was also the ultimate expression of help.

As we discussed these experiences, it seemed as if there were characteristics of the process of movement described by Rogers (1961). Abigail appeared to be able to show an increased openness to all aspects of her experience, and she stated that, in our sessions, she was able to share emotions which she had “walled off” from others. For example, Abigail described the desperate loneliness she felt, as she chose to manage the release of medical information to her mother. Another time, Abigail expressed the guilt she felt about her mother’s condition, questioning whether, if she had been living in the UK, she could have effected an earlier diagnosis of her mother’s cancer. Describing these emotions, Abigail sometimes had short periods of crying, as if she was beginning to experience these emotions physically.

However, despite this movement, progress appeared only partial. While we were discussing negative emotion, it felt as if our sessions often involved rational discussion rather than living the experience. Rogers (1961) suggests that feeling an emotion in the present, rather than reporting it as a past event, marks the increased fluidity in self-concept necessary for the full integration of experiencing. There appeared to be two reasons for this only partial progress.

Firstly, as Cornelius-White (2007) has argued, therapy is most effective when the therapist can accurately symbolise their own experience. As I describe below, I used supervision to help me understand how my presence in one particular session may not have maximised growth. But secondly, following reflections from Mearns and Cooper (2005) concerning relational depth, I hypothesised that Abigail was not yet ready to trust herself to feel these emotions. This seemed to be reflected in a comment Abigail made in session four when, after beginning to discuss the exhaustion she was feeling, Abigail spontaneously reflected that she couldn't face looking ahead. At the end of this meeting, and recognising the importance for the therapeutic relationship of considering tasks and bond, I asked whether approaching such emotions together was useful or manageable. Abigail said that she felt it was, and that these were issues she needed to address. We agreed she would warn me off if she were not willing or able to explore them.

5 Detailed exploration of session six

Whilst as Lietaer (1992) noted, client and therapist are frequently misaligned on the identification of helpful sessions, both Abigail and I agreed in a later review that this session was pivotal to change. I believe that the reason for this change - the dialogical encounter - underpins my theoretical argument for a two-person, rather than one-person therapy. While the session has many imperfections, the conditions driving the intensity of the encounter seem to tally with those proposed by Mearns and Cooper (2005) as characteristic of relational depth: a state of profound contact; both participants being fully real; and a mutual valuing of the other's experiencing. In this way, they propose, it is the encounter, and not simply the conditions, which is key to healing.

Abigail began by describing what she called "an awful week". Fearing their mother was going to die, Abigail and her brother challenged the medical team on their decisions about her mother's care. We discussed the anger Abigail felt about this treatment, and moved to talking about Abigail's sadness and exhaustion. At this point, sensing something more at what Gendlin (1984: 76) termed "the edge of awareness", I shared my impression of her feeling very

alone this week. Abigail responded by describing her fear of her mother's death, but also her difficult hope that her mother might die soon, both because her mother would be out of pain, and also because Abigail doubted how much more she herself could take.

Early in the session, Abigail's speech appeared bright and rapid with frustration, which I largely matched. As the subject matter changed, our voices became quieter and slower. As Abigail expressed the difficulty of coping, she began to cry. I sat with Abigail in silence as she cried, trying to support her through my gaze and my stillness. Abigail broke the silence by articulating her hope that her mother's condition would improve, but also an inner sense that this was unlikely. I felt I needed to provide an accurate empathic response (Mearns & Thorne, 1999) to affirm I was hearing and accepting what she was saying. I was aware Abigail had avoided using any "death" words, and my response was sensitive to that choice. Mearns and Cooper (2005) describe how, in facilitating relational depth, there is often a need to slow down to find time and words to address deeper feelings. I was conscious of this in the pace and tone of my response. Abigail seemed to be able to recognise and build on this empathy, as she elaborated on her sense of imminent death.

In his review of Rogers' empathic exploration, Greenberg (1996) highlights the value of patience. In various exchanges, we explored the difficulty of understanding her mother's exact medical position. In an empathic conjecture ("While one part of you is holding on to the hope, there's, there's this real feeling that [sighs] ... how much hope can there be, I suppose, now?"), I sought patiently to encapsulate the dilemma Abigail had been expressing, while encouraging deeper investigation of her experience: what Mearns and Cooper (2005: 121) term "knocking on the door". While I questioned in supervision whether I might usefully have focussed on the edge of awareness (e.g. fear and sadness that her mother would not survive), the conclusion was that greater attunement was demonstrated by my actual response, which aimed delicately to balance the conflicting emotions of hope and despair. From her subsequent statements, Abigail seemed to sense her ambivalent feelings were understood and validated, and this encouraged her to explore these negative feelings further.

Describing her mother's gradual loss of strength, Abigail voiced her sense that – for both her mother and herself – the fight for different treatments had resulted in a sense of despair: that “every corner has been a brick wall”. I was aware how Abigail's image suggested the hopelessness of her mother's situation. However, while recognising the therapeutic utility of metaphors, Rennie (1998) cautions that their exploration can detract from empathic following. Thus in my response (“It's difficult to keep believing when you can't find a way out”), I sought not to address the metaphor directly, but by extending Abigail's imagery in a gentle voice, to sense the struggle to maintain hope. Mearns and Cooper (2005) suggest relational depth involves being in a shared world, and Abigail's reply appeared to confirm my sensing of her experience, as she affirmed the imagery I had used by whispering “Yeah, there is no way out, I know that.”

As Abigail continued to acknowledge this situation, her voice tailed away and she began to cry once more. She quietly reflected that she had expected to have more time, and the chance to do more with her mother. Given our therapeutic goal of exploring difficult emotions, I decided to be congruent with my feelings, both as an expression of my empathy and also because they appeared related to our goal. In describing my deep sadness in hearing about these missed opportunities and lost hopes, my intent was to recognise what I felt to be the deeper edge of Abigail's experience, and also to embody the kind of presence which Bugental (1976) describes: both accessibility (willingness to be impacted) and expressivity (willingness to share oneself).

During the session, I was uncertain of the impact of my comments, as in her reply, Abigail reverted to exploring the impossibility of recovery, rather than engaging in the emotion (sadness) of the situation. Mearns and Schmid (2006) describe how an invitation to meet can be ignored, and in my next comments, I was concerned to rebuild our engagement through an accurate empathic response. However, I may have underestimated the value of my congruence. In our review after the next session, Abigail spontaneously recalled my disclosure, and reflected her sense that I cared about what she was feeling, not just as a therapist but as a real person. This perhaps suggests something

of the longer-term impact of encounter, and the mutual experience of being “touched by the essence of the opposite” (Schmid, 2002, cited in Mearns & Cooper, 2005:.42).

In re-engaging with Abigail’s situation, I sought to affirm my understanding of both the practical difficulties of caring, but with emphasis on the emotional strain of seeing someone you love so ill. My intent was to validate the pressure Abigail described in her most recent comments, while also directing the process towards the emotional impact of her experience. Examining Rogers’ empathic exploration, Greenberg (1996) remarks how Rogers focused selectively on the more painful, unexpressed emotions, while also prizing the client’s feelings. Abigail seemed to sense my understanding of her situation, and she expanded on the terrible sadness she felt at witnessing her mother’s decline. As she began to cry once more, she questioned – with what felt like a sense of despair in her voice – what the long term effect of this experience would be for her.

Feeling myself again touched by Abigail’s distress, it felt as if my response came from my core (“That you almost wonder what all this is doing to you, how it’s possible to bear all this, bear all this desperate sadness ... and fear”). My intent was to be alongside Abigail, by showing my empathy and acceptance for her fear and sadness. Furthermore, these empathic reflections were bound up in what Greenberg (1996) calls embedded process direction: a focus on what was most strongly felt, which I believed to be Abigail’s concern that she might not be able to cope. Brink and Farber (1996) describe how silence can be hard-working. I felt that our words, and the gaps between our words, carried a shared understanding of the sadness and despair. During this time, Abigail gazed intently at me, and I leant forward in my chair; it seemed, as Mearns (2003) suggests, that the silence was a time to slow down and hear ourselves.

After a long pause during which Abigail began to cry quietly, she half-sobbed “Just sometimes I want it to just stop....and it won’t”. In exchanges interspersed with silences, we gradually unfolded the intense strain Abigail perceived in needing always to be strong, and her sense that her mother was

no longer the mother she had known in the past. Seeking to focus my empathic reflection on what seemed most live and poignant (Freire, 2007), I affirmed that the Abigail had already lost something of the person she loved. In a tacit exchange, Abigail nodded, and her eye contact seemed to convey her sense of being understood, and a deeper level of connection in our relationship. Mearns (2003: 64) has observed that relational depth provides a feeling of safety, where more of the “unspoken relationship” can be brought into the open. This appeared to be the case in Abigail’s response, as she cried intensely: “Because the person I really want to hug me, comfort me, tell me it’s all right, is her, and she can’t, and never will again.” It seemed to me that Abigail was finally able to symbolise the impossible nature of her loss: that the person who was dying was the person she would previously have turned to for support.

In the silence following Abigail’s comment, it felt as if we were sharing the desperate sadness of Abigail’s situation. Cornelius-White (2007) suggests that the core person-centred conditions of warmth, empathy and congruence can be as well communicated through non-verbal as verbal behaviours. Choosing to break the silence, I affirmed my own sense both of the awful impossibility of her situation, and also my awareness that nothing I might say could diminish this loss. My response was “simply trying to be my feeling in relationship with [her]” (Rogers, 1961: 203), so as to further reflect these core conditions in my words. In empathising with the “awfulnessness” (Abigail’s expression from the the start of this segment), and sharing my sense of the tragic existential reality and the ultimate limitation of the therapist and the therapeutic relationship, it seemed as if the core conditions combined in what Mearns and Cooper (2005: 17) termed “genuine empathic acceptance”.

The empathy, acceptance and congruence I intended appeared to enable Abigail to elaborate in the final minutes of the session on the pain of her loss. She gave some poignant examples of what her mother’s death would mean for her, both practically and emotionally. As we discussed these difficulties, I reflected that “the love that comes from her won’t be there in that kind of way any more”. While seeking to empathise with her sadness, my intent in the use of the phrase “in that kind of way” was – very lightly – to signal something of

the changing perception of loss throughout bereavement (Worden, 1983). Greenberg (1996) suggests such a sense of context allows for the possibility of growth.

6 Progression of therapy after session six

Following session six, Abigail appeared more open and present to the difficult aspects of her experience. In discussing the actualising process, Bohart (2007) suggests such openness results in greater value being placed on congruence with oneself and with others. This openness and real-time experiencing of emotion was increasingly apparent in remaining meetings, but particularly in session seven, which both Abigail and I reviewed as another important encounter.

Session seven began with Abigail describing her desperate sadness at the death conversations she had had with her mother. Considering the subject and Abigail's heavy tone of voice, I voiced my sense of the significance of these conversations, but also checked whether Abigail was able to continue talking about her feelings. My congruence stemmed from awareness of my complex responsibilities as a therapist, which meant not only furthering our jointly agreed goals, but also ethically avoiding inflicting harm. Abigail decided to expand on her feelings of sadness and loss, and then chose to contrast these feelings with a new relationship which she described as "making her feel alive". Mindful of work by Angus and Rennie (1989), describing how metaphors often contain an underlying meaning context which can illuminate understanding, I offered a tentative process direction to explore the meaning of Abigail's phrase.

Abigail's response led to what I considered to be a hugely significant discussion, which indicated not only Abigail's increased openness to difficult aspects of her experience, but also our understanding of a third, overarching condition of worth. Abigail described how her mother's death would in many respects mean she could lead a new life; that she felt her mother had wanted – needed – her to lead "a perfect life" of professional job, marriage and money, which proved to both of them that life had not been de-railed by the struggles

of Abigail's childhood. However, Abigail wondered whether she might not be a "victim" in a different way, in that she had lived the respectable life her mother had wanted, rather than being true to her own feelings about those things she instinctively preferred. Rennie (1998) suggests that process identification can draw attention to the meaning of a client's experience, and so I commented on my sense of Abigail's troubled facial expression, and the difficulty of exploring these feelings at this time. Abigail responded by sharing that she felt disloyal; however, we then considered how the sadness (love) and release (anger) could both be true. Haugh (2001) observed that, through congruence, it is not that something new is perceived, but rather that something new is created. This seems an accurate comment about the integrated understanding reached in session seven.

In her study of clients' experiences relational depth, Knox (2008) notes that moments of deep encounter often have enduring effects. These effects include a sense of validation or healing which is a catalyst for change in the self; such change involves a more open relationship with oneself and with the therapist, where a wider range of feelings can be expressed. In the sessions comprising the second half of therapy (eight to fifteen), I perceived that Abigail was attending to a much wider range of thoughts, feelings and bodily experiencing, and aiming to integrate these aspects of herself: in the words of Rogers (1961: 181), she was exploring "being the self that one ... is". Moreover, Abigail's exploration appeared to reflect the dual process of bereavement which Stroebe and Schut (1999) describe, oscillating between the grief of her mother's death and consideration of how to address her own future life. These sessions involved exploration of different kind of relationships with her brother and her husband. Besides her love for her brother, Abigail acknowledged a sense of resentment that he had been supported when she had had to struggle, and she began to consider how she might interact differently with him. On her husband's return to the UK, Abigail chose to voice the fundamental concerns about the relationship which she had experienced for a while, but buried. She described finding their discussions sad, but also reported feeling an inner calm at their decision to separate, believing that significant differences in values and experience meant that she could only be more fulfilled – and more herself – in another relationship. Another important discussion involved her future work

plans, and later in this latter phase, Abigail began applying for jobs and courses which would enable her to pursue an altered career path, which she believed was more congruent with her values and long-term goals.

Discussing endings, Rennie (1998) considers the idea of the therapeutic relationship outlined by Bordin (1979), and the particular challenges in goal, task and bond in the last sessions. In our final review, Abigail and I assessed progress against our goal of understanding the reasons for her numbness, and what we needed to accomplish to end our relationship. Dingman (1996) notes that the process of change is rarely smooth or linear. Abigail continued to feel the intense exhaustion and sadness of looking after her mother; however, she also described an increasing number of moments when she was able to share this sadness with her mother, and she viewed this as important for both of them. Another ongoing challenge was the integration of what Abigail called “the good and the bad” feelings, and this difficulty was noticeable in Abigail’s unease before her marriage discussions with her husband.

However, as Mearns and Cooper (2005) describe, this transformation of her intra-personal relationship with herself – Abigail’s awareness and acceptance of her feelings of sadness, anger, resentment – seemed to be connected over the weeks to the changes I have described in her personal relationships and work plans. This is perhaps captured by a discussion in session twelve. As Abigail described her search for a new job, I observed a lightness in her manner and a smile on her face, and decided it might be useful to offer a process identification. Abigail commented that she felt an increasing sense of personal belief and freedom from expectations; when I hazarded a depth reflection that facing her mother’s death had given her confidence, Abigail replied that for once she had not looked on the bright side or made positive comparisons, but had faced the worst and found she was still standing. The experience of this, integrated with her practical and general skills, made her feel hopeful about creating a new life.

7 Evaluation of the therapy

7.1 Difficulties in the work and use of supervision

Supervision was used to enhance the scope of my work in a number of ways. As indicated previously, detailed examination of session recordings allowed me to review the value of particular interventions, and consider the impact of possible alternatives. However, I also used supervision to help me explore two wider concerns in my work with Abigail. The first concerned the quality of psychological contact. Wyatt (2007) argues that embracing a relational or two-person view of psychological therapy means the therapist has to be vigilant to the quality of psychological contact. In session three, I felt at times as if Abigail and I were having a productive discussion, but that the therapeutic edge had been blunted. Reviewing the work in supervision helped me understand how, as Toukmanian (2002) describes, I had been overly aware of my own subjectivity, due to concern about needing to manage the process. This had detracted from my attunement to Abigail's moment to moment processing, and the ability to sense behind what Abigail was saying. Discussions in supervision helped me re-focus on the conditions needed for empathic exploration.

A second concern related to Abigail's psychological state. Mindful of Abigail's previous experience of depression, and of the overlapping experiential symptoms of grief and depression (Parkes, 2006), I was aware of my ethical responsibilities as a trainee psychologist to ensure that Abigail was being offered appropriate support for her needs. Rennie (1998) mentions how meta-communication can be helpful in person-centred therapy, by being congruent about the purpose of communication and thus reinforcing the therapeutic alliance. At the two points of greatest distress, Abigail and I had productive conversations in which this concern was made transparent, and discussed between us. Through conversations with Abigail, and in confirmatory reviews with my supervisor, we agreed to continue with the grief work.

7.2 Evaluation of the work

Lietaer (1992) highlighted the difficulty of evaluating person-centred work. Discrepancies often exist between the interpretations of therapist and client, and, as in my work here, there can be an absence of paper measures. In an effort most accurately to assess the outcome, I have sought to use Abigail's own statements and behavioural changes as a measure of progress.

Considering such factors, I feel our work together was very productive. Abigail's regular attendance supported her statement that she felt that our work helped her address her original goal in seeking in therapy. In our penultimate review, Abigail described how her new understanding of the conditions driving her experience (being hard, being helpful, the perfect life) was helping her assess her choices within current and future relationships. This seemed to be reflected in behavioural and life changes, such as the move to separate from her husband, exploration of new career path, and discussions over the ongoing relationship with her brother. Moreover, Abigail stated that she no longer experienced the numbness which had brought her to therapy. We noted her increasing capacity to sense and voice the full range of feelings, both negative and positive; as Mearns and Cooper (2005) suggest, this intra-personal relating appeared to have enabled the greater congruence of feeling which Abigail perceived with her close family members.

Finally, Abigail's continued ability to care for her mother, while also beginning to assess future life directions, suggest that she was engaging usefully in the dual process which Stroebe and Schut (1999) describe. Within the loss orientation, Abigail's ability to sense and integrate the conflicting feelings about her mother appear to have enabled her to begin to accept the meaning of the loss; within the recovery orientation, understanding the conditions that shaped her own experiencing allowed Abigail to begin to contemplate a different future.

7.3 Learning about psychotherapeutic theory and practice

My work with Abigail has crystallised two important learnings about the meaning of relationship within person-centred therapy. The first issue is theoretical. Rather than a modernist, subject-object conception of classical person-centred therapy, I align myself with Schmid (2007) and Mearns and Cooper (2005), viewing the therapeutic relationship as fundamentally a two-person encounter. The writings of Jordan (1991: 82) make clear the implications of this for both therapist and client: "one is both affecting the other and being affected by the other: extending oneself out, and being receptive to impact." Moreover, as Schmid argues, perhaps our commitment to such presence as a therapist can be seen as an ethical responsibility to respond, within therapeutic boundaries. Certainly, this responsibility appears more significant if, as Greenberg (1996) proposes, change in person-centred therapy comes not just through the internal relaxation of conditions of worth, but from the experience of a caring relationship. My work with Abigail suggested that growth in a client is inextricably connected to the characteristics of relating described above.

Given the significance of this learning, my second issue concerns how the strength of this relationship can be better assessed in practice. Many person-centred practitioners (Lambert, Shapiro & Bergin, 1986; Lietaer, 1992) describe how clients and therapists often hold differing views about the relationship, both within the session and across the course of the relationship. Recently, Patterson and Joseph (2007) began evaluating formal tools to assess these areas of person-centred work. In my ongoing practice, I am committed to exploring how I might make use of such developments, to help me learn more about the kinds of relationships in which I am engaged, and their therapeutic value for my clients.

7.4 Learning about myself as a therapist

My personal learning derives from my theoretical learning. Accepting the concept of a two-person therapeutic relationship means there is an ongoing

requirement for me to uncover the “lace curtains” or “safety screens” behind which I am hiding. To be able to be fully present, and to be able to offer the accessibility and expressivity which Bugental (1976) defines as the hallmark of presence, I will need continually to explore my awareness of my own emotions, feelings and vulnerabilities. For example, in my work with Abigail, exploring my anxiety to manage process competently helped me clarify what was interfering with my ability to be present; examining the detail of session recordings in supervision helped me understand how, at times, a slight awkwardness with congruent interventions led to over-wordy responses. As a developing practitioner, I will keep seeking specialist supervision which can help me understand how I can make use of process ideas from experiential person-centred therapy, while staying fully within the relationship: something which Rennie (1998) acknowledges as a challenging task. However, my work with Abigail has also made me aware of the growth in my capacity to offer this two-person therapy. I feel this is in part due to a greater understanding about the technical and theoretical aspects of therapy, and in part due to deeper self-understanding. Rogers (1961: 22) suggested that “the more I am willing to understand and accept the realities in myself and in the other person, the more change seems to be stirred up.” As I approach the last months of my counselling psychology apprenticeship, I see the training not as an ending, but rather as a vantage point from which to view the personal work required on the road ahead.

8 Ethics

Full and informed written consent was sought for the recording and writing up of this work, before regular digital recording of sessions commenced. It was recognised that consent could be withdrawn at any time. Anonymity regarding names and identifying details was assured and implemented throughout this report.

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Section D: Research

**Cancer as biographical disruption:
Continuity and change in younger
women's identities following the
experience of breast cancer**

Abstract

This study sets out to explore change and continuity in the identities of younger women, following a diagnosis of breast cancer. Experience of breast cancer is associated with both general and clinical distress, and evidence suggests that younger women may be particularly at risk (Jim & Anderson, 1997; Soothill, Morris, Harman, Francis & McIllmurray, 2001). Such distress has recently been connected to the way identities are renegotiated after cancer, with acknowledgment of the individual's lived experience and the social context in which identities are crafted. However, previous research has focussed on the process of identity change and on consideration of particular identities, with little research among younger women with breast cancer. Adopting a critical realist epistemology, this research aims to explore the range of identities younger women perceive themselves to experience after breast cancer. This study will describe the content of these identities, attending to perceived changes following the cancer diagnosis, together with positive or problematic aspects of these identities and the salience of particular identities. Eight women (< 50 years; cancer staging 0-II) participated in semi-structured interviews, which were examined using interpretative phenomenological analysis. Three major, interconnected themes emerged. "Challenges to embodiment: The body does its own thing" described new embodied identities related to the alien nature of cancer, being reduced to a body, and a different appearance. "Negotiated roles: What am I looking for now?" described changes experienced in social role identities such as partner, mother, friend and work colleague. "Emotional-existential dilemmas: Re-learning what life's all about" records how participants positioned their identities differently in terms of their mortality, autonomy and life goals. These findings are discussed, with particular consideration of the way younger women's experience of changed identities can be illuminated by theories of biographical disruption (Bury, 1982; 1991) and discourses of bodily self-control (Lupton, 2003).

1 Introduction

Disease cannot be separated from other parts of a person's identity and life. Disease changed my life as husband, father, professor and everything else. [...] It was no small thing to rediscover myself as I changed. (Frank, 1991: 57)

1.1 Rationale for this study

Breast cancer is the most common cancer in the UK. In 2007 – the latest year for which figures are available – almost 46,000 women and 277 men were diagnosed with the disease (Cancer Research, 2010). This represents a fifty per cent increase in the incidence of breast cancer over the last twenty five years. Within this overall population, the proportion of younger women diagnosed with breast cancer has also risen. Recent statistics suggest that women aged 50 or under form approximately 20% of the total number of people diagnosed with the disease (Cancer Research, 2010). While there is greater knowledge about genetic and lifestyle factors (HRT, diet, exercise, contraception) which may affect onset of the disease, there is still considerable uncertainty as to the contribution of such factors within both the individual diagnosis and the rates of incidence across geographies. However, due in part to earlier screening and diagnosis, breast cancer survival rates are increasing. Approximately three quarters of people with breast cancer survive at least ten years after diagnosis, with higher survival rates among those whose cancer is at a less advanced stage (Cancer Research, 2010). Thus, each year, an increasingly large number of women (and men) are living a life which has been affected by the experience of breast cancer.

Being diagnosed with a life-threatening disease obviously causes shock and emotional distress. From a clinical perspective, the definition of emotional distress has focused on the inability to cope:

..a multi-determined unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. (National Comprehensive Cancer Network, 2002:3).

Reviews of psychological conditions have reported point prevalence rates for major depression in the 20-25% range, with incidence of adjustment disorders also recorded at a similar 25-30% level (Sellick & Crooks, 1999). Furthermore, a quantitative survey of American cancer patients indicated that the prevalence of psychological distress did not vary significantly across the course of the disease, excepting the terminal phase where quality of life issues acquired a greater importance (Zabora, Blanchard & Smith, 1997). However, it is not simply the scale of these psycho-pathological conditions which demands attention to the experience of breast cancer patients. Beyond the realm of clinical disorders, the large number of first-person accounts in books and chatrooms emphasises what common sense would suggest: that a breast cancer diagnosis causes huge disruption and emotional turbulence for the vast majority of those who are told they have the disease. In her review of such breast cancer narratives, Herndl (2006) argues that these accounts share a need to make some sort of meaning from experience. Through the unsettling of embodiment, women find themselves required to make sense of their multiple identities, both within time and across time.

Recent psychological research has confirmed the link between meaning and distress, as well as indicating different forms of making meaning. In a substantial quantitative study, Jim and Andersen (2007) investigated associations between cancer patients' social or physical functioning and emotional distress. The cross sectional (n=420) and longitudinal (n=227) surveys found that the effect of physical functioning on distress was partly mediated by measures of meaning in life, while the effect of social functioning was fully mediated by meaning. Moreover, in the second survey which consisted exclusively of breast cancer patients, younger age was associated with higher distress, irrespective of levels of functioning. The relationship between meaning and distress is extended by Bower et al (2005), who

considered how different types of meaning could be associated with distress. This substantial (n=763) longitudinal survey of breast cancer patients indicated that participants' continued to perceive altered meaning and vulnerability both five and ten years after diagnosis. Furthermore, while vulnerability was unsurprisingly a predictor of negative effect, it was the combination of vulnerability and meaning which significantly predicted positive affect. However, while firmly linking meaning with distress and/or positive affect, these studies' usefulness is limited by the restricted measures of meaning they employ: brief indicators of inner peace, personal growth, spirituality and loss in the first study; indicators of changed outlook (meaning) and bodily functioning (vulnerability) in the second. Fortunately, these deficiencies are addressed by separate work in the area of post-traumatic growth. In addition to confirming the potential for both positive and negative change or distress after traumatic events, Tedeschi and Calhoun (1996) suggest that such change is experienced in three main areas. These are identified as perceived changes in the self (issues of strength and self esteem); a changed sense of relationships with others; and a changed philosophy of life.

Psychologists and medical professionals have explored these forms of meaning in two main approaches. The first – and by volume of studies, more predominant – approach has been a focus on 'adjustment'. This has involved an assessment of the ways behaviour is altered to accommodate cancer (Cella & Tross, 1986; Ell, Nishimoto, Morvay, Mantell & Hamovitch, 1989), or cognitive strategies used by people with cancer to respond to the life changes which can cancer bring (Jim, Richardson, Golden-Kreutz & Andersen, 2006; Parle, Jones & Maguire, 1996; Watson et al, 1988; Watson et al, 1991). Yet as Mathieson and Stam (1995) have argued, the dominance of this approach risks ignoring other aspects of the construction of meaning. The concern, they propose, is not that patients do not engage in cognitive activities as a result of their cancer, but rather "the extent to which this theoretical stance is an adequate description of the lived experience of a chronic, life-threatening disease" (1995: 286).

As a result, researchers have recently sought to explore changes to identities in the face of chronic illnesses such as cancer. Such projects do not see cancer

as a personal problem to be solved, mainly through the adoption of appropriate coping strategies. Instead, as Mathieson & Stam (1991; 1995) suggest, this body of research adopts a broader conceptualisation of the impact of cancer. Studies approach meaning as emerging through the lived experience of illness: an experience which may be located in the individual body, but created through the individual's existence in a social world and medical system. As I shall argue below, these meanings are established through the identities which are available to, and created by, people with cancer. This was something which became clear to me in my own experience with breast cancer, which preceded this research. Following my diagnosis, I was aware of the way in which my own choices, and the social (friendship, professional, medical) context in which I lived, were implicated in change to a number of identities. The meanings I attached to my life were bound up with those identities.

The focus of this study is thus inspired by personal and professional considerations. Building out from my own experience, it was clear that the growing incidence of breast cancer among younger women – approximately 9000 women diagnosed each year in the UK – means that many women like myself experience either general or clinical levels of distress. While one way of exploring such experiences has been through assessment of cognitive adjustment, I propose to take an alternative route which is more consistent with my own lived experience of breast cancer. This involves an attempt to understand the changes in a woman's life-world through their manifestation in the different identities she holds.

Before considering these specific identity questions, I will set the background for this study by outlining some relevant theoretical issues of identity. In this introduction, the term 'identity' will be used to refer to the theoretical concept of identity, to an overarching sense of self or to single self-as-object formulations such as 'mother' or 'partner'. This varied usage is common in existing identity research, although I have aimed to minimise confusion here by clearly describing the context in which the word is used. The term 'identities' will be used to describe multiple self-as-object formulations.

1.2 Defining the field: Some relevant issues of identity

Despite the dramatic rise in the number of studies of identity in the past sixty years, prominent academics have acknowledged the difficulty of defining the term, calling it an “open problematic” (Wetherell, 2010: 3) or an “essentially contested concept” (Mathieson & Stam, 1995: 287). While I recognise the amorphous nature of identity, I have also found it important to draw some boundaries which can focus enquiry in this study. To this end, I have utilised a definition of identity taken from Thoits and Virshup (1997: 109): “who I am in my own and others’ eyes”. In invoking the mutual interdependence of self and society, this definition alludes to several important aspects of identity which have relevance to this research.

Perhaps the most significant tradition underpinning this research is that of identity as a “subjective individual achievement” (Wetherell, 2010: 3). In this way, identity belongs to a particular person, and is both continuously located in a body and also inextricably linked to a particular place in society. Thus identity, as Erikson (1950) proposed, is a way of achieving personal coherence across a life-time, through the reflexive integration of biological and social factors which influence an individual across the years. Such biographical coherence was reinforced in Erikson’s theory by a progression through universal stages (child-adolescent-early adult-old age).

Thinking within the experiential traditions – phenomenology, existential and humanistic theory – has shaped understanding of this subjective aspect of identity. As Stevens (1996) argued, there are three main principles underlying this understanding. The first is that we experience ourselves as existing in the world. We derive our identity from the particular perspective we have on the world, and that perspective is gained from our location in our bodies. Indeed, as Merleau-Ponty (1962) proposes, our body and mind may be seen as inseparable:

The body is the vehicle for being-in-the-world, and having a body is, for a living creature, to be involved in a definite environment, to identify oneself with certain projects and be continuously committed to them. (Merleau-Ponty, 1962: 94).

The meanings and identities we draw from our experience come from the relationship between our bodies and other objects in the world. Although such meaning may be constructed, it is derived from “real” objects and is therefore not simply “within the head”. A second experiential principle concerns our human capacity for reflexive self-awareness. This capacity is essential to the creation of identity, as it forms a basis for the action we take in our lives. Linking reflexivity to earlier ideas about the body, experiential traditions would argue that, though inseparable, mind (reflexiveness) and body are not identical: that “consciousness is “being-towards-the-thing” through the medium of the body” (Merleau-Ponty, 1962: 159-160). Finally, the combination of our embodied nature and our reflexive capacities means that there is a dynamic quality to our existence. We are always in the process of becoming, and as active intentional agents we seek to realise goals, in identity as in other areas.

However, while describing the fundamental importance to identity of the intentional and embodied nature of human beings, experiential psychologists would also acknowledge how identity is simultaneously and vitally shaped by our situation in the social world. Here, identity is affected by our social location in particular groups and categories which are viewed to have similar or defining characteristics. These include wide-scale social categories such as gender (Bem, 1981), as well as more specific social roles such as mother, daughter or doctor (McCall & Simmons, 1966/1978), and even considerations of personality characteristics such as being a helpful or lazy person (Stryker, 1985). However, at the same time as raising up issues of similarity, research into social identities also stimulated awareness of social differences. Elias (1991) argued that people’s contrasting stakes in social life – positions of advantage or disadvantage – profoundly affected the nature of identities which individuals are able to craft. Thus, as Wetherell (2010) proposes, a more complex notion of identity emerges where an ‘identity slot’ – working class woman, Muslim woman – could be argued to precede the individual, fundamentally colouring the reflexive world and available possibilities for that person.

Furthermore, Wetherell describes how research linking identities to social categories also highlighted the constructed nature of meanings and significances attributed to bodies. Of relevance to this research is the ongoing debate about the biological and social construction of gender, with a recent publication by Fine (2010) arguing that it is societal rather than neuro-scientific factors which lead to the creation of gendered identities. Disability is another area which has emerged as a politicised social identity. Here, as Garland-Thomson and Bailey (2010) indicate, the construction of meanings has resulted in segregation of, and discrimination against, particular bodies. In his seminal work on stigma, Goffman (1963) described how certain physical characteristics could be defined as dangerous or discrediting, reflecting social perspectives on what was valuable or acceptable. Thus a stigmatised social status might affect a woman's subjective identity, through an individual's relations with strangers and intimates.

This brings us to the important question of how subjective (or personal) identity and social identities can be integrated. Indeed, as Wetherell (2010) describes, the theories of knowledge of many social scientists would lead them to deny that such a question is actually necessary: for some sociologists, the individual is entirely social; for many experimental social psychologists, the only real and determinate unit is the individual. But for those researchers like myself, who see both personal and social identities to be vitally important perspectives within the overall field of identity, such responses are inadequate. Instead, the idea of a dialectical relationship between the individual and society offers a way forward. Building out from the debates between structure and agency which Giddens (1991) articulates, this dialectical relationship involves a circular process between the individual and society. The individual takes up aspects of social material, modifies it to suit her position, and then communicates this modified material back into society, where it becomes part of the new corpus of social material.

Wetherell (2010) suggests that such a process has historically rested on "binary distinctions between 'interiors' and 'exteriors' " (2010:12). Thus theories of the self proposed by Mead (1934) comprised an 'I' which was the locus of agency and unique individuality, while the 'Me' was created from the

internalised attitudes of others. However, recent work has proposed a more dialectical relationship between the I/Me. Jenkins (2004) argues that the development of identity should properly be seen as an ongoing dialogue between personal self-definitions and definitions of identities offered by others. Moreover, in re-asserting the importance of language, reflexivity and social interchange to identity development, Jenkins suggests some modifications to Mead's original processes. Following the tradition of Kant (Glover, 1988), the 'I' becomes the capacity of the self to reflect on itself, and thus to self-realise and self-monitor; this 'I' is actively bound up in assessing and evaluating possibilities for the 'Me' available through social interaction, and – as we shall now consider – through the regulatory and evaluative discourses available in society.

This discursive turn in psychology further complicates conceptualisations of identity. The essential question asked by discursive approaches was whether identity and experience were straightforwardly given by social location. This more 'critical' approach focused upon the ways in which accounts of experience were constructed, through detailed analysis of the workings of language and human meaning-making. While the interactive creation of meaning in conversation formed one aspect of discursive approaches, another important aspect was the investigation of broad knowledge regimes and positions. Such discourses can be described as:

...ways of referring to or constructing knowledge about a particular topic or practice: a cluster (or formation) of ideas, images and practices, which provide ways of talking about forms of knowledge and conduct associated with a particular topic, social activity or institutional site in society. (Hall, 1997: 4)

More than simply ways of talking, discourses in this sense become "regimes of truth" (Macleod, 2002:23), where particular positions (such as those of the medical/psychological professions) are constituted as expert scientific knowledge, while other positions (such as lay women's experiences) are constituted as having lesser value. As Willig (2001:107) has argued, these dominant discourses "privilege those versions of social reality which legitimate existing power relations and social structures".

In addition to exploring such regimes of truth at the societal level, research in identity has considered how particular discourses are taken up and used by individuals. As I shall describe below, my research does not take an extreme discursive position, where individuals are seen as being constituted entirely by the social identities of which they are composed. Instead, as Walkerdine and Bansel (2010) have proposed, individuals can be argued to orient themselves reflexively to cultural resources for making sense of their identities. This applies equally to embodied identities as to social role identities. In her exploration of body projects, Woodward (2000) talks of the ways in which the body can become a site for the construction of identity. Discourses concerning shape, colour or features promote a social position as to what is valued, thus becoming the means through which a person can – to some degree – negotiate the value or stigma which becomes attached to the individual body.

This range of contradictory discourses, and the multiplicity of identity positions, has led many to seek to “rescue experience, self-knowledge and authenticity from the discursive onslaught” (Wetherell, 2010:15). Many post-positivist realist researchers (Alcoff, 2010; McAdams, 1997) now argue that multiplicity and fragmentation have gone too far, and that exclusively discursive examination of identity and the self ignores persistence, repetition and order across time. From such a viewpoint – which this study shares – it is not so much that individuals’ identities are created by discourses and structural positions. Instead, people collaboratively create these identities for themselves, through dialogue on both the interpersonal and social levels. This means, as Wetherell (2010) proposes, that the constitution of identities is not transparent, but rather requires careful investigation. Moreover, research in this area need to consider the “intersectional nature of identity” (Crenshaw, 1991). Rather than thinking of identities in terms of discrete categories, exploration of this subject must take into account the inter-relationship between different aspects of identity, such as embodiment and roles.

This section has described how human lives can be understood to be formed of multiple identities. These identities are rooted in our bodies and are actively and continuously constructed, as well as being simultaneously personal and

social. The next section will consider how issues of identity and cancer have been explored in the existing research literature, with particular attention to the circumstances of younger women with breast cancer.

1.3 Linking experience of breast cancer with identity

The complexity of research in the area of cancer and identity reflects something of the complexity in the area of overall identity studies. There has been no systematic pattern of studies, no one methodological approach and certainly no meta-analysis of results. This means that some aspects, such as the process of change in identity, have been more extensively covered, while detailed research into individual identities is less comprehensive. Moreover, while some studies are directly focussed on women with breast cancer, the absence of a substantial literature on breast cancer and identity means that I have also drawn on other work which offers indirect evidence of issues in this area.

In evaluating this literature, I have remained focussed on two questions. What evidence is there for change in identities after cancer? If identities are being altered, what kinds of changes are taking place? In order to impose some structure on this analysis, I will begin with a review of studies whose broader research objectives provide insight across a range of identities. This will be followed by a review of studies which have assessed the impact of cancer in a specific identity area. To assist understanding, a glossary of frequently used cancer terms is attached as Appendix 1.

1.3.1 Issues of identity and cancer – general studies

Although not focussed on identity, research by Ganz et al (1996) provides a helpful starting point for this survey. The study aimed to understand the psycho-social concerns and quality of life of women diagnosed with early stage breast cancer (Stages 0-II), and used mixed methods (surveys, clinical measures and semi-structured interviews) as well as a longitudinal frame to assess changes at one, two and three years after treatment. A number of

interesting findings emerged from the study. Firstly, a generic measure of functioning (the Medical Outcomes Study) suggested that these women were performing well in terms of meeting role and social requirements, when compared to people with other chronic illnesses. Thus on one level, breast cancer might appear to have less impact on identities than other illnesses such as heart disease and arthritis.

However, results from separate assessments of quality of life, sexual functioning and marital functioning presented a different picture, with significant declines in scores across the time of the study. These global scores were illuminated by participants' statements at interview, and by responses to a Cancer Rehabilitation Evaluation System (CARES) questionnaire, which provided details of important and severe problems. In terms of bodily issues, approximately 70% women reported a reduction in energy and difficulty with physical activities, even three years after surgery; when assessing their body image, approximately half of the women described being embarrassed to show their body, and being uncomfortable with scarring and body changes. In discussion, women linked these issues to surgery and to subsequent treatment. Both mastectomy and reconstruction were associated with pain and lost sensation, while nausea and changes in hair texture and breast form were connected with chemotherapy and radiotherapy, and ongoing hormonal treatment was held to be responsible for difficulties associated with premature menopause, such as hot flushes and vaginal problems. These bodily changes were in turn directly implicated in sexual functioning. At the same three year point, 47% women reported they were not interested in having sex, while scores on decreased frequency of intercourse, difficulty becoming aroused and difficulty becoming lubricated were 48%, 48% and 64% respectively. In terms of relationships, 20% women felt that their partner did not take sufficient care of them, or that it was difficult asking for care; for those who were dating, 56% women expressed difficulty in meeting dates and 39% expressed fear of initiating sex. There were, however, more positive expressions about relationships, with approximately 33% women in relationships perceiving that their relationship had improved through cancer. Finally, while other issues were accorded lower severity ratings, there were also notable scores for

psychological distress (frequently anxious 51%/frequently depressed 50%, at the three year point).

How does this research inform our understanding of possible identity issues after cancer? In their study, Ganz et al (1996) isolate many difficulties which would appear to translate into challenges to identities: challenges to sexual identity; embodied identities; identity as a partner; potential impact on a range of identities through reduced levels of energy. These issues are persistent, continuing several years after the end of treatment, and are experienced by women who were diagnosed with less advanced breast cancer. Some support for the changes in these identity areas comes from research by Soothill, Morris, Harman, Francis and McIlmurray (2001), whose examination of the significant unmet psycho-social needs of cancer patients indicates issues with changed body and appearance, altered sexual functioning, and management of others' perceptions and feelings. However, there are a number of important limitations in the research of Ganz et al, both in general and from the perspective of my particular focus. There are no baseline reads of any of the research measures, and so while change following cancer may be inferred, it cannot be clearly measured. Relatedly, the particular impact of cancer on sexual or marital functioning cannot be directly assessed, as there is no control group of women without breast cancer. The quantitative nature of the study means that there is little detailed information about particular identities, while use of questionnaires (and questionnaire-led interviews) means that the study is firmly oriented in the psycho-social research model of the researcher, rather than in the lived experience of the participants. Lastly, with an average participant age of 58, the changes recounted by these women may be less relevant to the younger women I am considering. Indeed, the previously mentioned study by Soothill et al found that younger people were more likely to experience unmet needs than older people with cancer, although the age band for this category of "younger people" was not defined in their write up.

A wider body of research has examined identity issues from the perspective of the person with cancer. As Riessman (2003) has described, these studies emerged as a response to the bio-medical focus on technical factors of disease, and the consequent neglect of a very different phenomenon: the patient's

experience of illness. In this area, an important source of evidence is the study by Charmaz (1995), which describes how serious chronic illness “undermines the sense of unity between body and self and forces identity changes” (1995: 657). In her investigation of the way body and self intersect in illness, Charmaz interviewed mostly older men and women (n=55, 60+ years old) with a variety of conditions including cancer. Charmaz proposed that underpinning change in identity was experience of an altered body, and this experience seemed to take three forms. Firstly, there were physical changes such as new (and potentially distressing) bodily sensations and impaired functioning. One participant described how activities she used to do easily were now a challenge. Secondly, participants described experiencing a radical disruption in their previously held notions of body and self; rather than a body which was taken for granted, there was a heightened awareness of embodiment, and a disturbing sense of the body as disconnected from the self and out of control. Thirdly, issues relating to bodily appearance – both the presence of visible changes, or the absence of visible changes which could helpfully signal potential changes in functioning – affected participants’ ability to maintain their previous roles. All these changes to the body were experienced in a social context, and so could be associated with guilt and shame: guilt due to perceived failure to meet social standards of bodily performance and appearance; and shame because “their very existence testifies to a failure to meet these standards” (Charmaz, 1995: 663).

While all participants described alteration in their experience of their body, Charmaz (1995) argued that such bodily changes do not automatically result in changed identity goals. In some instances, completion of treatment might leave participants with a greater appreciation of their restored physical state, leading to the resumption of previous identities as a work colleague or development of new identities through leisure pursuits or work ventures. However, participants also reported how markedly altered bodily functioning undermined identities such as a mother or a work colleague; this could result in lowered expectations or limits being imposed as to the scope of a particular identity, or tradeoffs being made between identities. Again, Charmaz suggested that these changes needed to be contextualised. For example, in the area of work, identity goals were more easily maintained when participants

had greater positional power within their employment; moreover, those with more money and help appeared to have more choice over the types and timings of any tradeoffs in identity. Age also presented itself as a factor, with Charmaz proposing that practical and emotional support from partners was less apparent for younger women than for older participants in the study.

One important link between changes in embodiment and identity goals is more fully documented in an earlier study by Charmaz, which explores loss of self through chronic illness (Charmaz, 1983). Linking with ideas of stigma outlined by Goffman (1963), participants with chronic illness perceived themselves to be discredited, through both the evaluations of others and also through failure to meet their own expectations. This could affect identities in a number of ways. Some participants with visible impairments – an amputated leg from diabetes, a slower gait due to rheumatoid arthritis – described being publicly mortified or discredited by other's reactions to their changed body, leading them to restrict certain activities and identities. Other participants with less evident but potentially "discreditable" conditions such as diabetes described carefully planning social activities such as parties to manage potential embarrassment.

In summary, then, the work of Charmaz (1983; 1995) provides important insights as to the impact of cancer on identity. Firstly, the research suggests that cancer results in significant changes to perceived embodiment, which can frequently translate into changes across a wide range of role identities: work colleague; partner; mother. By anchoring her research in the participants' life-world, Charmaz indicates the dynamic relationships between these different aspects of identity, and also the way in which an individual's identities are shaped by particular features of their context (class and age), and by social valuations which ascribe stigma to particular physical and social qualities. However, there are also some limitations in this research. The wide focus on changes in body and self mean that, while bodily changes are covered in more detail, changes in role identity are only briefly recounted. The older age, mixed gender and spread of chronic illness among participants mean that the applicability of these findings to younger women with breast cancer cannot be assumed. Finally, the symbolic interactionist perspective within which Charmaz

views her work appears to frame particular aspects of her enquiry. Thus while structural and interactive aspects of social context are considered, issues of discourse are not mentioned in these studies. Furthermore, the conceptualisation of identities appears to be restricted to the area of social roles, with the body seen as the foundation of identities but not as a source of identities in its own right.

How can other general studies of identity support or extend the findings of Charmaz? Several pieces of research have examined the process of creating meaning following cancer. There is some question as to the applicability of the findings to this study, as the participant groups have had multiple cancers and diverse stagings (O'Connor, Wicker & Germino, 1990; Mathieson & Stam, 1995), as well as a seeming bias towards participants with dominant religious faith (O'Connor et al). Despite these issues, and although the focus of these projects has not involved systematic exploration of individual identities, both studies enhance understanding of the kinds of identity changes which can ensue. This is the case in the research of O'Connor et al , who explored through semi-structured interviews the personal search for meaning in people with breast and lung cancer (n=30). O'Connor et al suggested a number of ways in which social roles might be altered. The physical and logistical consequences of cancer treatment could interfere with the immediate involvement in role identities; for example, one participant talked of finding it harder to take care of friends, while another regretted the interruption to his work as a taxi driver. However, participants also described how cancer led to an increased sense of unpredictability about the future. This provoked an assessment of the value of previous roles, which could result in a number of actions. People in the study mentioned cancer being a spur to taking up new activities; many also talked of a deeper appreciation of friends and family members, and of choosing to invest more time in these relationships. This is echoed in a separate case study from Finlay (2003), where diagnosis of multiple sclerosis led a woman to withdraw entirely from her professional work in order to become a full-time mother: a clear prioritisation of this particular identity.

Such changes in social roles hint at a further level of identities, which can be read from the research from Connor et al (1990). These identities relate to an individual's personal qualities and their status as a human being. One woman who had had a mastectomy extrapolated from her physical condition to her state as a person, perceiving that "it's not as if I'm a whole person right now" (1990:171). In assessing how the cancer might have occurred, some participants reviewed their behaviour and whether they might have contributed to the cancer through their stressful lives or smoking habits. Almost all participants mentioned thinking about the possibility of death, and acquiring greater awareness of their mortality. Thus there appeared to be a deeper sense of the existential nature of being a human. This is also reflected in research by Little, Paul, Jordens and Sayers (2002), which suggests that cancer can pose existential issues in two ways: firstly, by profoundly disrupting role identities; and secondly, by asking individuals to consider what it means to be a mortal person. Additional evidence for this kind of change comes in studies by Anderson and Martin (2003) and Kayser and Sormanti (2002). In the former, a woman with cancer describes a new sense of herself as a courageous person, as a result of coming through the fear and physical challenges of her diagnosis and treatment. In the latter study, approximately half of the respondents (n=41) described themselves using personal characteristics such as strong, self-confident, and a fighter, suggesting cancer had heightened their awareness of these personal qualities.

Thus the research of Connor et al (1990) supports and extends earlier findings concerning the change in role identities, while also suggesting that cancer may lead to change in a different set of identities, which are more psychological or existential. A second study throws different light on the kinds of identity changes cancer can bring. In their qualitative study (n=39), Mathieson and Stam (1995) sought to understand the process of giving meaning to illness, within the context of social relationships and the medical system. The orientation of this work deepens understanding of the way in which societal practices can be implicated in changes to identity. One way in which this may occur is through issues of stigma. Mathieson and Stam state that all but two participants mentioned stigma-related issues at some point during the interviews, although a question about stigma was never asked. Linking with

the work of Charmaz (1983; 1995), participants' accounts describe how a sense of stigma began through the implicit contrast between the changed, ill body and the previous "healthy" body. This was exacerbated through awareness of the powerful stigma of body cues, such as visible scars left from surgery or hair loss following chemotherapy. This in turn led to changes in social interactions. Some whose cancer was made visible by treatment described experiencing altered relations through others' sympathy and pity. For others, identities were negotiated through selective monitoring of relationships, which could involve either the non-disclosure of cancer or a decision to withdraw from friendships.

A further way in which societal practices were implicated in identity change was through the medium of medical treatment. Some described how their sense of themselves as human beings was minimised through medical professionals' focus on their disease status. This "objectifying the illness" (Mathieson & Stam, 1995: 295) often meant impersonal communication and a sense that the medical details of the disease, rather than other aspects of life, were the only valid areas of experience. Furthermore, in taking up the potentially unfamiliar identity of a patient, participants were required to learn information about their disease and the forms of medical talk, and then to decide how they might structure their new role. Davis (2008) has suggested that medical literature communicates a vision of a "good patient" as one who works co-operatively with doctors, and is vigilant and attentive to her body. However, participants in Mathieson and Stam's study describe how their sense of what is required of a patient – presentation of exclusively medical issues – leads to a perception that the broader impact of cancer within their lived experience is disregarded ("To express concerns – it's just not part of the process, like you don't go in and have chemo and talk about the experience" – 1995: 299).

So, in assessing general psycho-social and identity issues following cancer, there appear to be a number of broad conclusions. Firstly, several different kinds of identities appear to undergo change following cancer. There are changes in roles and also in a more nebulous area of psychological/existential identities, as well as more expected changes to embodied identities. These

changes are sometimes experienced positively, through heightened appreciation of physical or personal qualities; however, in many instances, these changes are perceived to have negatively affected an individual's identities, by restricting their activities or reducing their self valuations. Within the wider social context, the nature of change is often shaped by the social stigma which is attached to cancer, and by the style of medical practices.

There are, however, some important gaps in the evidence. Much available research has not investigated the particular situation of women with breast cancer. Furthermore, the specific circumstances of younger women have also not been properly addressed. Finally, despite a wealth of general information, there is no comprehensive investigation of the range of identities affected by breast cancer, and nor is there a systematic and detailed examination of particular identities. In the second part of this review, I will consider to what extent research into particular identities following breast cancer modifies this picture.

1.3.2 Issues of identity and cancer – research into specific identities

In my initial examination of the literature, I was surprised by the very limited number of studies exploring the intersection of breast cancer with specific identities. There was a small number of studies dwelling on motherhood or being a survivor. However, despite several alternative searches, I found little specific information on the impact of breast cancer on identities repeatedly alluded to in the general studies: being a friend, a partner or an employee. In order to frame what was potentially a search of infinite regress, I made the decision in the case of these identities to consider studies whose particular focus was psycho-social issues. This enabled me to give some shape to most identities. However, as I shall discuss later, the incomplete nature of this information added focus to my research design.

In considering change in the identity of a mother with breast cancer, two studies were of particular interest. Elmberger, Bolund, Magnussen, Lutzen and Andershed (2008) conducted a qualitative project (n=20) to understand how women perceived breast cancer to affect their ability to be a "good mother".

Their research suggested that cancer not only presented a challenge to their previous conceptions of “good mothering”, but also affected other aspects of identity. Many women described a struggle to meet the practical needs of their children, while experiencing changes in their body, such as fatigue or nausea. Being a mother during cancer was associated by many women with preserving some kind of normality for their children during the women’s cancer treatment. This involved work at the practical level - ensuring previous routines were continued – and also at the emotional level, where many mothers described presenting a “happy face” (2008: 61), in order to hide their fears from their children. Another aspect of this altered role was responding to their children’s emotional reactions to cancer; this could require coping with reluctance to bring friends home if the mother had no hair, dealing with silence or – more cheerfully – receiving encouragement from children to keep going through treatment.

In the study from Elmberger et al (2008), and also in separate research by Kayser and Sormanti (2002), women with breast cancer describe wrestling with a balance between their perceived responsibilities as a mother and care of their own personal needs. Kayser & Sormanti discussed how many women appeared to maintain a high level of caregiving, despite the emotional and physical costs to themselves; for others, cancer acted as a catalyst to rethink the balance of care for self and others. In their research, Elmberger et al suggested that many participants managed this balance by making trade-offs with other identities: for example, by preserving energy through limiting non-family social contacts, avoiding people they found difficult to handle, or reducing work hours. These changes appear to reflect the higher prioritisation of health and families which Kayser and Sormanti observed in many women’s response to breast cancer. By being grounded in the lived experience of women, and through a focussed engagement with issues of motherhood following breast cancer, these two studies appeared to offer valuable insight into the extent and form of change for younger women (mothers) with breast cancer.

Being a “survivor” had been explored from both quantitative and qualitative perspectives, with contrasting views as to the nature and significance of this

identity. In a large scale quantitative survey of cancer patients (n=321: breast cancer = 41%), Deimling, Bowman and Wagner (2007) asked participants to assess themselves against any or none of the descriptors of cancer patient, cancer victim or cancer survivor. 86% respondents identified as a survivor, with 42% as an ex-patient, 13% as a patient and 13% as a victim. Similar response levels were received in a cross-sectional questionnaire-based study of cancer patients (n=168) from Park, Zlateva and Blank (2009). In this case, 83% endorsed the survivor identity, 81% person who has had cancer, 58% patient and 18% victim. Deimling et al observed that the identification with multiple identities indicated the uncertain nature of cancer, and resulted in people with cancer seeing themselves as simultaneously located in multiple positions. The team also reported that identification as a survivor was associated with cessation of cancer symptoms, a generally optimistic personal orientation and also with successful treatment results. Citing responses to an attribution of the salience of this new identity, Deimling et al proposed that 66% respondents perceived that "being a cancer survivor is an important part of who I am" (2007: 762). However, as part of an additional analysis, the researchers also noted that 60% participants had not disclosed their cancer to other people, casting some doubt over the strength and nature of their sense of survivorship.

Other research suggests that survivor identity might owe more to the constructs of researchers than to the perceptions of people with cancer. Kaiser (2008) undertook qualitative research among women with breast cancer (n=39), to understand the extent to which survivorship was embraced and the meanings which the identity was felt to hold. The author commented that her participants almost never referred to themselves spontaneously as a survivor. When asked whether they saw themselves as a survivor, the identity polarised responses. Some felt that they were able to take up this new identity, but only with extensive and varied crafting of definitions which included personal strength, being engaged in an ongoing war, and being a survivor of life in general. A similar number of women rejected the identity, for equally diverse reasons: uncertainty at having survived; not experiencing their health as seriously jeopardised in the first place; and a refusal to be part of what they perceived as the social identity of a breast cancer survivor.

How can these different accounts of the survivor identity be reconciled? One possibility is that the different methodological approaches ask for different responses from people with cancer. When directly prompted with choices which range from survivor to victim, participants may choose to align themselves with those identities which appear to be most associated with longer and more fulfilled life: that of a survivor. Therefore, there may be demand characteristics inherent within the surveys. However, as Kaiser (2008) argues, it may also be the case that this identity is - to some degree - a professional construct, which "supports the medical model wherein illness is diagnosed, treated and cured" (2008: 86). In the lived experience of women, this identity seems to have less salience, and to hold confusing and ambiguous meanings.

Despite the - at times - conflicting evidence, the experience of being a survivor and a mother following breast cancer have at least received some attention. By contrast, there are few identity studies to guide understanding of the impact of breast cancer on being a partner, a friend or an employee/worker. In the absence of specific identity research exploring women's experience of being a partner through breast cancer, I considered how psycho-social studies might give some sense of this experience. It surprised me that many such studies explored the area of partnership in cancer through attention to the perceived reactions of the person with cancer's partner. Such attention appeared to be influenced by evidence that the quality of support received from the partner is associated with a patient's positive adjustment to cancer (Lichtman, Taylor & Wood, 1987; Northouse, Dorris & Charron-Moore, 1995).

However, this approach appears to assume a uni-directional nature in relationships, and to pay insufficient attention to the way in which the experience of cancer is played out through the interactions of both partners. Bearing in mind these limitations, cross-sectional (n=170) and longitudinal (n=49) studies from Wimberly, Carver, Laurenceau, Harris and Antoni (2005) provide useful information as to the ways in which the perception of a partner's emotional involvement and initiation of sex, together with a positive first sexual experience after cancer, are associated with many aspects of breast cancer patients' wellbeing (psychosexual adjustment, emotional distress and

marital satisfaction). A quantitative survey (n=66) by Brusilovskiy, Mitstifer and Salzer (2008) affirmed these findings, proposing that women with breast cancer who perceived their partners' "intimate" adaptation to be positive, experienced significantly lower distress. Working from a more systemic perspective, Northouse (1990) conducted a descriptive longitudinal research project (n=82) to compare the psycho-social adjustment following mastectomy of breast cancer patients and their husbands. Assessing the experimental group against a non-cancer control, Northouse found that both patients and husbands exhibited higher distress scores eighteen months post-surgery; although the group average level of distress was at a mild level, 35% patients and 24% husbands reported moderate to severe distress at this stage. Northouse therefore suggested that adjustment within a relationship was not a self-limiting event that resolved itself within a month or two of surgery, but an ongoing process; moreover, that there was a sub-group of patients and husbands who were at a higher risk of long-term problems.

While these previous studies on partnership involved quantitative assessments, research from Kayser and Sormanti (2000) provided a rare qualitative viewpoint. Their research involved exploring the impact of cancer on a woman's relationship, with a particular focus on the kinds of support received. While the study's participants (n=40) experienced a range of cancers, the focus on younger women (M = 36 years) has relevance to this study. Kayser and Sormanti found that more than half the women reported changes regarding the performance of household chores and in decision making practices, with the partner frequently taking on new responsibilities. While two thirds of participants described a higher level of emotional closeness, one third felt that they were more distant from their partner. Furthermore, although almost half the participants felt they received adequate support from their partners, those who desired more support typically identified emotional responsiveness (offering comfort and reassurance; talking and listening more) as the area which was lacking. The large majority reported that sexual activity had significantly decreased.

In summary, then, diverse sources of evidence indicate that a woman with breast cancer may undergo substantial change in her identity as a partner, with

negotiation of emotional, sexual and practical issues. While the nature and the potential distress implicated in these changes appears to have been sketched out, the details of the lived experience of women within relationships have been barely studied. The study from Kayser and Sormanti (2000) provides a useful comparison point for my research, being grounded in more substantive accounts of individual relationships. However, the variety of participants' cancers in their project, and the particular attention to issues of support, may have directed attention to certain aspects of experience at the expense of others.

While building understanding of the previous identities required considerable investigation, similar searches for the identity of friend during cancer revealed very little information. The importance of social support in helping individuals manage difficult experiences has long been documented within the psychological literature (see Miell & Dallos, 1998). Specifically within cancer, a quantitative study (n=133) by Waxler-Morrison, Hislop, Mears and Kan (1991) indicated that social support had independent effects on the survival of women with breast cancer. The number of supportive friends, the extent of contact with friends and the size of the woman's social network were all found to be associated with survival. In autobiographies of people with cancer (Diamond, 1998; Lucas, 2004; Moran, 1989), the importance of both the practical and emotional support of friends is frequently recounted. These accounts also allude to problems in friendship, due to others' perceived reactions to cancer, as mentioned in the previous section of this chapter. However, understanding of the identity of friend from the perspective of a woman with breast cancer appears to be missing in the formal psychological literature.

The availability of relevant research appeared to be only slightly better in the area of the final identity which I examined: that of being a work colleague or employee. The direction of research conveyed an impression that the intersection of cancer and work was explored mainly from the perspective of employers, as a means of supporting productivity, rather than from the perspective of the employee. However, these studies provided information which suggested a number of possible aspects to the work identity following cancer. Research from de Boer, Taskila, Ojajarvi, van Dijk and Verbeek (2009)

indicated that people with cancer were more likely to be unemployed than a control group. The scale of this meta-analysis (reviewing 26 individual studies, with a diversity of cancers) conceals the effects of cancer staging. However, it is interesting to note that women with breast and reproductive cancers were significantly more likely to be unemployed than a non-cancer control group of women, whilst there was no difference in employment rates between experimental and control groups in the male cancers (testicular, prostate). This suggests there is an interaction of gender and cancer in the employment identity. A further study by Hassett, O Malley and Keating (2009) indicated that the age of women diagnosed with breast cancer had an impact on their employment status. Through quantitative assessment of a health claims database (n=3233), the researchers found that the vast majority (93%) of employed women with breast cancer continued to work after treatment, although both type of treatment (particularly chemotherapy) and older age (>54 years) were associated with stopping work.

However, a study from Johnsson, Fornander, Rutqist and Olsson (2010) indicates that many other factors beyond gender and age are implicated in changes to this work identity. This narrative analysis of women with breast cancer (n=16) suggested that, while the study's participants described wishing to return to work, their experience of cancer had altered their perceptions of the value of employment. Moreover, when considering the narratives of those women who had returned to work and those still on leave, a distinguishing characteristic appeared to be the perceived quality of social support from employers and co-workers. Thus the existing research literature – though partial and varied – appears to suggest that there can be considerable change in woman's work identity following breast cancer, and that may be influenced by a number of factors.

I will now draw together the implications from the review of generalised and specific studies of identity and breast cancer, before considering the research aims of my own study.

1.3.3 Conclusions from existing research into breast cancer & identities

Following my initial personal and professional interest in issues of identity in the wake of breast cancer, I was surprised to find that the current research literature does not appear to have explored this area in particular detail. As described in this chapter, a number of studies suggest extensive change in bodily, social and psychological identities following cancer and – to a limited extent – breast cancer. Despite this fact, the range of identities affected by breast cancer has not been systematically or explicitly explored, either in general studies or through a diverse range of research projects into individual identities. As a result, the nature of change in particular identities has also not been considered; nor have any broader issues which might link these particular changes. The situation of younger women with breast cancer has been especially overlooked, and their particular life stage – in the midst of active engagement in potential identities as mothers, employees, partners – might be seen as putting them at especial risk for disruption and emotional turmoil. This may underlie the higher levels of distress reported by Jim and Anderson (1997) and Soothill et al (2001).

The absence of such research appears to be an important omission, if identities are seen as the place in which the meaning of cancer is located. Through an exploration of the lived experience of breast cancer, it will be possible to understand the dialectical relationship between the individual woman and her social environment, which Wetherell (2010) described. Improved understanding of the nature of such identities will benefit counselling psychology in many ways. Firstly, it may assist psychologists working therapeutically with younger women with breast cancer, by offering perspective concerning the utility of current counselling practices and ideas for new therapeutic work. This accords with recommendations in the national Cancer Reform Strategy (2007), which requires health professionals to offer good psychological support services throughout the cancer journey. Secondly, it may open up consideration of wider social issues concerning the task of managing breast cancer within the UK society. Finally, given the widespread incidence of

breast cancer, reading this research may assist counselling psychologists on a personal level, in responding to their own – and others’ – experience of cancer.

1.4 Research aims

Overall research question:

What perceptions do younger women have of the identities experienced after breast cancer?

Specific research aims:

1. To understand the range of identities younger women perceive themselves to experience after breast cancer
2. To explore the content of these identities, considering
 - any differences in identities held before and after the cancer diagnosis
 - any positive or problematic aspects of these identities
 - the salience of, and links between, different identities.

2 Methodology

I am not the outcome or the meeting point of numerous causal agencies which determine my bodily or psychological make-up. I cannot conceive myself as nothing but a bit of the world, a mere object of biological, psychological or sociological investigation. I cannot shut myself up within the realm of science. All my knowledge of the world, even my scientific knowledge, is gained from my own particular point of view, or from some experience of the world without which the symbols of science would be meaningless. (Merleau-Ponty, 1962: ix)

2.1 Overview

Having introduced and specified the research question in the Introduction, in this chapter I set out the methodological approach I have taken – my own particular “point of view” - in exploring this question.

My account begins with the choice of a qualitative perspective, and here the rationale for my choice is intertwined with the characteristics of the qualitative perspective, and so I have presented this section as such. I continue by outlining the epistemological parameters which frame my particular study, and seek then to show how these are reflected in the choice of method: interpretative phenomenological analysis. This leads to details of how the study was carried out and elaboration on the process of data analysis. The chapter closes with sections which address how the credibility of this study might be evaluated, and a discussion of the ethical considerations which informed the work.

I have been aware that my methodological approach to the research question has inevitably contributed to the context of the phenomenon I am exploring, and I have aimed to draw out these influences within the ongoing discussions.

However, there were also wider reflexive issues relating to issues of method, and I have addressed these in a separate section which closes the chapter.

2.2 Rationale for a qualitative perspective

My fundamental reason for choosing a qualitative approach was the kinds of answers which it would provide to my research questions. My understanding accorded most strongly with Willig (in press), who suggests that qualitative research is driven by a focus on meaning. This meaning is subjective, and drawn from participants' accounts of their own experience. A qualitative study will therefore use an inductive, "bottom-up" approach to explore the texture of experience; it will seek to describe or possibly interpret experience, rather than to quantify phenomena or predict causal relationships. This focus on subjective experience and meaning anchors descriptions in a particular context, which also becomes part of the meaning. Langdridge (2007) describes how this context can include the intersection between the personal life and the historical, cultural and structural settings within which a person moves. Thus the kinds of answers possible from qualitative research are subjective, contextual descriptions or interpretations of meaning drawn from an individual's lived experience. The nature of these answers seemed to me to fit most appropriately to the nature of my research questions. Given the limited and partial scope of existing research in this area, a qualitative approach would allow me to produce work which provided new and unexpected insights as to the individual, social and cultural aspects as reflected in women's sense of their identities following cancer.

My second motivation for choosing a qualitative approach was that this perspective explicitly acknowledges what Woolgar (1988: 10) terms "the methodological horrors". The issues of indexicality (how an explanation is tied to a particular circumstance), inconcludability (that no explanation is ever full or final) and reflexivity (that researcher characteristics shape attention and perception) are worked with and struggled over, rather than denied. Given my awareness that my own particular experience of cancer had stimulated my research, a qualitative method would enable me explicitly to consider these

issues as they related to this study, as well as to my participants' experience within the research.

Political issues underlined my final reason for settling on a qualitative approach. As Kitzinger (1990) has argued, the fact that qualitative research is grounded in lived experience means that it is better able to respect the meanings of participants. The inductive nature of this approach allows those taking part in research to give voice to their experience in a more extended and less controlled way than in quantitative studies. This was important to me, as both my own contact with cancer and my work as a trainee counselling psychologist suggested that this opportunity was only rarely accorded to patients within the medical treatment process. Moreover, as a member of the counselling psychology profession, I wanted not only to work within the healthcare system, but also to consider what changes need to be made to the system. The explicit acknowledgment of indexicality within qualitative research means that, alongside personal descriptions, it can also be possible to explore political meanings. I conceived of this research as grounded primarily in the understanding of experience, and it was possible that the participants might themselves raise issues of power and positioning. However, following Kitzinger and Hollway (1989), I was conscious of wanting to avoid the trap of substituting personal accounts for political ones, but instead to be able to illuminate dominant social practices and power relations implicated in the way women make sense of their experience. Thus the adoption of a qualitative approach enabled me not only to raise up women's accounts of their experience, but also put forward a consideration of conditions bound up in this phenomenon.

This brings me to a discussion of the epistemology and method.

2.3 Epistemological framework

Flew (1989) suggests that epistemology is the exploration of what we know, how we know, and whether or if we can know. When considering the latter issue, I perceive that my research is anchored in a world which I can know. My belief is that there are underlying phenomena and structures which exist, but that our perception of these phenomena is – to a greater or lesser extent- mediated by our own individual perspective: our social situation; our biological state; historical and cultural contexts. Thus I situate myself within critical realist approaches, as described by Parker (1998). These epistemological beliefs do not rest on proof, but upon two arguments. Firstly, following Greenwood (1994), I believe that social determinants do not refute underlying phenomena. For example, although the way we talk about or act on emotions may reflect contextual influences, it does not follow that these words or actions do not relate to underlying emotional processes or entities. This feels particularly important when considering the material reality of a cancer tumour. Secondly, following pragmatists such as James (1890), I consider that belief in a reality beyond my experience is indispensable to the organisation of that experience: it helps me begin discussions with medical professionals, or argue over the distribution of tangible resources. So in answer to the question of whether I can know, I believe that I can access some knowledge of the world, although this knowledge will be affected by both my own position and the position of that which I am considering.

This leads to the question of what I know. Willig (in press) has usefully expanded this issue, arguing that a researcher must warrant not only the status of the data, but also the status of the analysis of the data. Turning to the status of the data, and in the light of the theory of knowledge outlined above, I believe that this research does in a large degree correspond to a 'real world' which is shared and inhabited by others. Participants' views are statements shaped by constructions drawn from their personal situations and choices, and from the cultural and historical resources available to them. However, these statements also correspond to an underlying social, biological and existential reality which can be comprehended and used by others.

Similarly, considering the status of the analysis, I believe that research is inevitably affected by the individual characteristics of the person collecting and analysing the data. However, providing that these personal characteristics are adequately explored and evaluated – something I shall discuss further below – then I consider that such data can provide knowledge not only of the participants' worlds, but can also be used to create a dialogue with other research considering related aspects of this shared world.

Returning to Flew (1989), my final challenge is to consider how I know. Here, understandings of epistemology overlap with beliefs about ontology. My argument is that knowledge is derived from three sources: from our essential subjectivity; from our existence in a social world; and from our physical bodies. Considering the ideas of Heidegger (1962) concerning Dasein (or "being-in-the-world"), Langdridge (2007) suggests that the concept of an individual viewpoint is inherent within the correlation between what is experienced and the way something is experienced: "Dasein is an entity which is in each case I myself: its being is in each case mine" (Heidegger, 1962: 150). This reflects my personal belief in the ability of an individual to explore and make sense of the world, underpinned by the notion of reflexivity or self-awareness. However, in a rejection of simplistic Cartesian theory, I believe that while our human position is essentially subjective, it is also inevitably connected to the context in which we find ourselves. Again following Heidegger (1962), this being-in-the-world means that the physical, psychological, social and historical nature of our situation are the background against which we work out our individual positions. Furthermore, both our being-in-the-world and our reflexivity are fundamentally dependent on language, which Heidegger (1947: 217) notably described as "the house of Being". Yet while perceiving language to be critical to subjectivity and the social world, it stands in a more problematic relation to the third source of knowledge. Burkitt (2003) explored the idea of a field of being, which includes the human body but of which the body is only one aspect. He bases this conception on ideas from Merleau-Ponty (1968: 248): "this flesh of my body is shared by the world, the world reflects it, encroaches upon it and it encroaches upon the world". Burkitt goes on to suggest that meaning is not derived primarily through language or reflection, but through the "sensible-sentient body" (Merleau-Ponty, 1968: 136). The

implications of accepting this aspect of knowledge are several. Firstly, it links with the idea of reflexivity, in that an individual's knowledge can be seen to be tied inextricably with physical being: what Merleau-Ponty (1962: 231) termed "the body-subject". Secondly, it connects with existential issues outlined by Heidegger, in his proposition that our being is ultimately a being-towards-death: our situation in the world is defined by the transience of our flesh and of the world surrounding us. Finally, it brings us back to questions of realism, relativism and inconcludability. Grounding knowledge in this field of being implies a world "out there"; as Merleau-Ponty (1968: 133) suggests, that "there is a world, there is something....there is cohesion, there is meaning". However, this realism is limited by the problem that language can never fully capture what Burkitt (2003: 331) terms "the mute world of the sensible", and so there must be a constant dialectic between language and these pre-reflective sensings.

I shall take these considerations further in the next section, when I explore my particular research method, and the kinds of knowledge it can facilitate.

2.4 Interpretative Phenomenological Analysis (IPA)

2.4.1 What is IPA?

Smith, Flowers and Larkin (2009) view IPA as a qualitative method which examines how people make sense of lived experience. It aims to gather detailed material which captures the quality and texture of this experience. A researcher will invite accounts from participants, with the focus of such accounts often resting on events of especial significance, such as changes in health or personal status. Once recorded, these accounts are analysed by the researcher, whose findings are perceived not only to be grounded in the data – the participants' interpretation of their experience – but also to involve an inevitable interpretation by the researcher: what Smith and Osborn (2003: 51) termed "the double hermeneutic", or two-fold aspect of meaning-making.

Smith et al (2009) suggest that IPA does not operationalise a particular idea, but draws on several philosophical traditions. Drawing from phenomenology, Smith et al (2009) argue that experience is reflexive, situated, embodied and existential. IPA acknowledges the significance of Husserl (1982), who advocated that science should be grounded in personal experience; it was only through attentive, systematic examination of awareness that science could develop second order concepts and theories. However, Husserl also suggested that this awareness is problematic, because to understand the things themselves, we need to strip away our pre-conceptions and 'bracket' habitual ways of viewing phenomena. Smith et al argue that the ideas of Heidegger (1962) and Merleau-Ponty (1962) have also been formative to IPA. As described above, the concepts of Dasein and the body-subject propose that human experience is shaped by our physical bodies, our social context and our capacity for self-awareness. Moreover, citing Merleau-Ponty, Smith et al suggest that the individual physical unit of our body means that our relationship to others must begin from a position of difference. We can never entirely share an experience, because our experience is rooted in our individual embodied position. Furthermore, Smith et al invoke the ideas of Sartre (1948) to suggest that the phenomenon of experience is contingent upon the developmental and processual aspects of being. Awareness of death, absence and the time-bound nature of existence are inherent in our experiencing.

Underpinning the interpretative aspects of IPA, Smith et al (2009) ground the method in the tradition of hermeneutics. Human reflexivity means that IPA must be inherently interpretative, and Smith et al theorise ways in which IPA can work with the interpretation of the double hermeneutic. Firstly, they invoke the idea of the hermeneutic circle. Following Gadamer (1990), they suggest that assessment of experience is always based on prior assumptions, but that these assumptions can be made manifest and modified through contact with experience. Therefore understanding comes from a dialogue between the researcher's assumptions and an account, not from the extinction of the reflexive self: "the important thing is to be aware of one's own bias, so that the text can present itself in all its otherness, and thus assert its own truth against one's own fore-meanings" (Gadamer, 1990: 269). Thus IPA will involve an iterative cycle of interpretation between the researcher and the account, and

between the parts of the text and the whole of an account. Smith et al suggest that IPA also works with interpretation by adopting a stance towards the status of an account. Based on the ideas of Ricoeur (1970), they propose that IPA occupies the centre ground between a "hermeneutics of meaning-recollection" (an unquestioning and essentially realistic acceptance of the status of participants' accounts) and a "hermeneutics of suspicion" (a critical analysis of the structural influences underpinning a particular account). This means that IPA must fundamentally be grounded in the details of a participant's life world, but should also consider as part of its interpretation the nature of the situated experience which is being described.

Finally, Smith et al (2009) suggest that IPA is anchored in idiographic traditions. They argue that this involves a focus on the particular, both through a concern with detail and through the perspective of a particular person and context. However, they challenge the idea that this equates to an exclusive focus on the individual, suggesting that although a person may be uniquely embodied, their experience is always situated and relational. This idiographic focus means that while multiple accounts may be reviewed to gain understanding of a particular kind of experience, the distinctive voices within each account need to be preserved while considering shared themes.

2.4.2 Considerations in using IPA

There are a number of reasons why I judged IPA to be an appropriate method for this study. An important consideration was a match between the broadly critical realist stance which IPA adopts, and my own epistemological position. As Willig (2001) describes, IPA accepts some element of construction on behalf of the researcher and the participant, but holds that there is an empirical world out there which must be respected. I believe that this tension between phenomenology and interpretation is relevant and useful in answering my research question, and has previously been shown to be valuable in examining health issues (e.g. Bramley & Eatough, 2005; Brewer et al, 2007; Murray & Harrison, 2004).

Another consideration in the choice of IPA was the flexibility of its method. This meant that participants are typically given considerable latitude in the manner and content of their responses, and researchers have many options in the form and type of questioning they adopt. This flexibility seemed to offer most opportunity for participants to explore a range of meaning, and to consider the cognitive, affective or embodied aspects of the phenomenon. However, it also enabled me to ask questions of participants (Smith & Osborn, 2003) if aspects of experience appeared to be missing or only partially disclosed. This led me to prefer IPA over alternatives such as narrative analysis, where, as Herndl (2006) describes, the narrative connectedness can result in the painting of an unproblematic picture. I felt that in this research such selection would impede my gathering the fullest description of experience.

The complex role of the researcher within IPA was also an important factor in choosing this method. Willig (2001) has criticised the method for the lack of clarity in the researcher's position, and whether she is "discovering" or "constructing" reality. My understanding of the role I have undertaken in this research is that I am doing both – and that it is by doing both that I will be able to make better sense of the phenomenon. For example, in the course of field work and early stages of analysis my focus is on detailed understanding the participants' experience: mostly discovery, but some construction due to the inevitable subjectivity of researcher and participant positions. In later analysis and discussion, I will be using these "discoveries" to construct links with more conjectural or theoretical levels of interpretation.

Despite enthusiasm for the potential of IPA to provide meaningful answers to my research question, I am nevertheless mindful of its limitations. As Willig (2001) argues, perhaps the most significant of these limitations is the reliance of IPA on the representative validity of language. Eatough and Smith (2008) acknowledge that while IPA enables some consideration of how language shapes experience, it does not permit analysis of how individuals are constructing themselves and others in their use of language; nor does it allow more radical explanations of the structures in society and the ways in which these constitute individuals. From a political point of view, IPA studies may

therefore provide a less aggressive challenge to existing systems than radical constructionist research.

Willig (2001) suggests that a further issue with the IPA method is the challenge of obtaining suitable accounts. She argues that participants' creation of these accounts requires insight, personal strength and sophistication of understanding. While acknowledging the appropriateness of this challenge, I believe that it is an issue relevant to many, if not all, qualitative approaches. The difficulty of achieving and accessing reflexivity, and of gaining nuanced accounts which adequately capture lived experience, is not unique to IPA.

A final criticism of IPA raised both by Langdridge (2003) and Willig (2001) concerns the phenomenological status of IPA. Here the problem appears to lie in the role of cognition. Langdridge proposes that cognition is not properly a part of phenomenology, which is more appropriately focused on the pre-reflective characteristics of experience such as feelings and moods on the edge of consciousness. However, my own awareness of phenomena accords with the arguments of Smith et al (2009), who propose that experience contains both pre-reflective and reflective activity, and both are proper subjects of attention in phenomenology. Thus while research may strive to uncover perceptions which have previously not received conscious attention by participants, it will also attend – as part of the effort to understand being-in-the-world – to those embodied cognitions with which an individual approaches a phenomenon.

Having explored in detail the main characteristics and parameters of IPA, I will now discuss how this method was applied in my particular research study.

2.5 Research plan

2.5.1 Choice of data collection method

Smith et al (2009) argue that, to obtain the detailed subjective accounts required for an IPA study, interviews and diaries have to date proved the most appropriate data collection methods. Although I examined the use of diaries in the work of Boserman (2009) and Smith (1999), I decided that semi-structured interviews would better enable me to find answers to my research questions. Kvale and Brinkman (2009) discuss how the inter-subjective context of the interview provides an opportunity to explore ambiguous and contradictory statements, as well as to raise or legitimise the more sensitive topics that might be ignored in diaries. I felt my experience as a counselling psychologist in training equipped me to create a dialogue where topics could be explored and expanded, and to sense where aspects on the edge of awareness could be productively followed up. Furthermore, I also responded to Kvale and Brinkman's belief that there is an ethical element behind the choice of an interview format. While mindful not to move the status of the meeting from a research interview to a therapeutic counselling session, both my own history and the research literature (e.g. Aaronson, 1991) suggested that an interview could in part be a witnessing of experience, and in some sense, a way of giving something back to participants for their involvement in my research.

Drawing on Flowers (2008), I chose to do one-off rather than multiple interviews. This design places a greater pressure on the interviewer to build rapport quickly and to ensure the interview schedule has been fully covered. However, I perceived these disadvantages to be outweighed by the advantages: more coherent narratives resulting from the simpler design; and the practical benefits to participants from having to tell their story only once.

2.5.2 Initial interview structure

In developing an interview schedule, I used guidance from Smith and Osborn (2003). The order and content of the initial schedule were based on my

research questions; these were translated into more accessible language, with follow-up prompts based on areas suggested by the literature review in my research proposal (Appendix 2). However, during a reflexive interview to raise my awareness of my own cancer experience, significant issues in interview structure became apparent. My initial schedule asked participants to describe the identities which they felt had existed before cancer, and then to review those which they felt they held now. Aside from the phenomenological issues concerned with a retrospective assessment of the past, this temporal shift resulted in a disconnected interview, with what seemed to me like an excessive degree of researcher intervention. Furthermore, my initial schedule began with an outline of past and present identities, to be followed up with a more detailed explanation later. Yet this partition meant I experienced my account as being abruptly terminated at the start; I was delivering pieces of information to the researcher, but not being able to get into the flow of describing my experience. I felt frustrated and as if my story was being “managed” by someone else.

My experience of my initial schedule during this reflexive interview led me to develop a substantially revised schedule for the pilot study. This involved adapting the Twenty Statements Test (TST: Kuhn and McPartland, 1954) as a stimulus for qualitative research into identity issues. In its original conception, the TST asked participants for spontaneous responses to the question “Who Am I?”. These answers were coded and quantitatively assessed to measure conceptualisation of, and attitude towards, the self. Kuhn (1964, cited in Turner and Schutte, 1981) described how this conceptualisation was founded on underlying identities:

Central to an individual’s conception of himself [sic] is his identity; that is, his generalised position in society deriving from statuses in the groups of which he is a member, the roles which stem from those statuses, and the social categories to which his group memberships lead him to assign himself. (Kuhn, 1964: 630-31).

In adapting the TST for qualitative work, I felt that participants could be asked to write down who they felt they were after their experience of cancer. These responses could then be explored one by one in conversation, with the

researcher asking questions to understand the meaning of these responses: what the response alluded to; the positive or negative emotions attached to the response; and any ways in which this response was affected by social structures outside the participant.

Two questions needed addressing with this new format. The first was how to gain understanding of change in identity since diagnosis with cancer. I decided this could be best accomplished by asking participants, during the exploration of each response, how they felt this area had changed since their diagnosis. While this still involved an element of post-hoc reconstruction, I felt this approach at least had the merits of being faithful to their perceived experience of their identities in the present. The second question was how to raise identity issues which I considered might be relevant but had not been included in participants' list of responses. This involved sensitive areas such as sexuality and femininity, which have been documented in several studies (e.g. Ganz et al, 1996) as problematic and often hidden aspects of women's lives after cancer. I was also aware that any identity not immediately included could be sensitive for an individual, although on face value seeming less controversial (e.g. working woman). Following advice on interview schedule design in Kvale and Brinkman (2009) and Smith et al (2009), I decided that a full exploration of the phenomenon meant I should try delicately to ask about these "missing" identities. However, this questioning would take place after discussion of participants' spontaneous responses, when participants might be better placed to gauge whether this was something they wished to express to me, and with the recognition that participants might prefer not to answer.

This revised interview structure concluded by asking participants to consider those identities most important to them following their cancer diagnosis, and how this had changed since before cancer. This new schedule was written up (Appendix 3) and used as the basis of a pilot study.

2.5.3 Pilot study & revised (final) interview structure

There is some debate about the different functions of pre-testing, with Yin (1994) distinguishing between pre-studies which involve exploration of

different possible options and those which constitute a “dry run” of procedures. In line with Robson (2002), I viewed my pilot study as a dress rehearsal of the interview format I hoped to run on a larger scale. My objective was to understand whether the interview schedule would enable me to gain the rich, detailed accounts I was seeking, within an appropriate time frame. As importantly, I was also seeking to ensure that the schedule was stimulating but also sufficiently comfortable for a participant.

Given my desire for explicit and frank feedback on their experience of the interview schedule, I chose to do this pilot work with a woman connected to me through a friend. Madeleine¹ was exactly representative of my proposed sample. In telephone discussions prior to meeting, we discussed that, although she would be helping me test and critique the interview schedule, Madeleine also felt she would benefit from exploring her experience in a detailed way. Despite the more informal contact, I ensured that full recruitment and consent procedures were followed.

The pilot study was run exactly as the interview study described below. Results and feedback from the pilot were both positive. The TST device generated a personalised “agenda” for the interview which allowed Madeleine to tell her own story in a rich and detailed way. In her feedback, Madeleine said that she felt that she had said “all the things that I needed to say”, and that taking part in the interview had been both enjoyable and insightful for her. Moreover, although she had been surprised by the request to complete the TST sheet at the start of the interview, she found that it had made her respond to the question spontaneously and in a different way from the way she would normally have told her story (i.e. chronologically). Therefore, the TST had provided an efficient and productive way of gaining access to her experience. In terms of exploration of sensitive issues, I found that an alternative way of addressing these questions might be to raise them where an appropriate opportunity presented itself.

¹ Not her real name.

In summary, then, the pilot study reassured me that the revised interview schedule was able to provide rich, detailed and meaningful data for both the researcher and the participant, and that this data addressed the main research questions identified for my study. My next step was to organise the full-scale study.

2.6 Participants

Smith et al (2009) recommend that homogeneity is sought among participants in IPA studies, to further the method's objective of illuminating a particular experience. However, they also suggest that the criteria for homogeneity depend on each individual study. The first criterion put forward is theoretical: what factors are indicated in research as important influences of experience? The first factor indicated was a focus on the experience of women aged between twenty eight and fifty years old. Studies from Bower et al (2005) and Soothill et al (2001) indicated that the need for self-transformation appeared to be experienced most acutely by younger women, perhaps due to the cancer presenting a more unexpected threat to still-developing identities. An additional selection factor was for participants to have been diagnosed with cancer between four and eighteen months before their response to the research flyers. This related to indications in research by Bower et al; although change continued to be experienced many years after cancer diagnosis, the first eighteen months appear to involve the most active renegotiation of self-image. In a similar vein, I chose to recruit participants for whom this was the first diagnosis of cancer, and whose diagnosis specified an early staging of the disease (Stage 0, 1 or 2). Although I was not able to find formal research literature to justify this choice, many books written by women with cancer (e.g. Kuner, Osborn, Quigley & Stroup, 1999) suggested an earlier staging (0-2) defined qualitatively different experience from a later staging (3-4). Finally, treatment modality – surgery, radiotherapy and/or chemotherapy – was not chosen as a screening factor, as studies by Carpenter, Brockopp and Andrykowski (1999) and Bower et al suggested that change is experienced across all treatment types. Details of actual participants are summarised in Table 2.1 below.

Age (years) at diagnosis	Mean=42	Range=36-50	
Ethnic origin	All White		
Location	Leeds: 4	London: 4	
Time (months) since diagnosis	Mean=11	Range=6-18	
Cancer staging	Stage 0: 2	Stage 1: 4	Stage 2: 2
Cancer treatment	Surgery: 8	Radiotherapy: 5	Chemotherapy: 2

Table 2.1: Summary of participant characteristics

Smith et al (2009) also raise the issue of practical criteria for participant selection. My consideration of such issues was weighed with another aspect not raised by these authors: the ethical criteria underpinning selection. Given the large number of women who fitted my theoretical criteria, I decided I would select purely in order of response to recruitment material. To facilitate arrangements, all participants needed to be able to speak, write and understand English. While recognising that the requirements of the study might have led to some self-selection, my political desire for the study to be open to anyone who felt able to participate meant that I chose not to screen by educational background or occupation.

To understand what socio-demographic factors might be implicated in the experience of my actual participant group, I asked each participant to consider completing an optional questionnaire which reviewed these factors (Appendix 4). The actual participant group were all of Caucasian origin; this was not by intent, but due to implementation of my previously mentioned recruitment procedure. I hypothesise that the lack of ethnic diversity may reflect user characteristics at the host charity, but may also be related to cultural patterns regarding treatment of cancer, as I shall consider in the Discussion. A further practical consideration at the screening stage was that participants should not have another chronic illness such as heart disease, as this might muddy their ability to attribute meanings gained from cancer alone. Finally, to safeguard the welfare of participants, I decided that I would screen for a history of major psychiatric illness or moderate-severe depression and anxiety. My judgement

was that there was a greater, unacceptable risk that women in these situations could find the research distressing, rather than enabling.

2.7 Sampling plan and sample size

As Smith et al (2009) describe, IPA studies seek participants who have experienced a particular phenomenon. This requires purposive sampling. To this end I established a connection with Breast Cancer Haven (BCH), a UK charity which offers support to women diagnosed with breast cancer, and gained permission to advertise my research to their clients (see Appendix 5). Participants were recruited by placing flyers (Appendix 6) in the reception areas of the Leeds and London centres of BCH. In line with the findings of Aslam (2006), flyers were coloured yellow to attract attention.

Although Brocki and Wearden (2006) noted the wide range of sample sizes used in previous IPA studies, they also observed that a consensus towards smaller numbers had emerged. Considering the objectives of this research, I felt that a sample size of eight participants would enable me to explore adequately each person's experience, while also providing opportunity to consider convergent and divergent perspectives of the research phenomenon. As each participant would be interviewed only once, this total of eight interviews fell within the range of four to ten interviews suggested by Smith et al (2009) as being suitable for the scope of practitioner doctorate research.

2.8 Procedure

A potential research collaboration was agreed with the BCH charity, and research approval sought from City University, London. At this stage, I began a reflexive journal, which considered personal and theoretical aspects shaping research development. Following decision on the IPA data collection method, I developed an initial interview schedule. A research colleague interviewed me using this initial schedule, providing both reflexive and schedule-specific learnings. With the exclusion of recruitment, all aspects of field work –

telephone screening interview, consent forms, revised interview schedule – were then evaluated in a pilot study. Following a successful pilot, flyers were distributed in two BCH centres. I conducted telephone interviews (see Appendix 7) with respondents to describe the purpose and nature of the study, to verify inclusion criteria, and to describe the significance of informed consent. All those who met inclusion criteria and expressed interest in participating were sent an information email or letter, confirming the telephone conversation and re-confirming interview details (Appendix 8).

Interviews took place at BCH centres. Prior to starting each interview, I asked participants to sign a consent form (Appendix 9) to show that they understood the purpose of the research and what was required of them. This form also included consent to audio-tape the interview, and to the subsequent publication of material from the interview, subject to confidentiality requirements. I then asked participants to complete a questionnaire concerning demographic and cancer treatment information (Appendix 4). Semi-structured interviews were conducted with each participant, according to the revised interview schedule (Appendix 3). Each interview lasted between ninety minutes and two hours. Interviews were transcribed verbatim. Prior to starting analysis, I undertook a further process of reflection, including further consideration of autobiographical areas influencing my research and an exploration of my outsider/insider status. I analysed transcripts by examining one interview in detail before going on to others, using the process documented in Smith et al (2009). Following initial readings of the first transcript, I noted preliminary insights, observations and comments concerning use of language right hand margin. I then reviewed the transcript again to establish emerging themes. These themes were at a higher level of abstraction but remained grounded in the participants' lifeworld. The themes were noted in the left hand margin. Emergent themes were then analysed for connections, and grouped together where appropriate into super-ordinate concepts. Throughout these stages, I used an iterative process of analysis, checking my interpretations against supporting data in the participant's account. To complete the analysis of this first account, I tabled super-ordinate concepts under the participant's name and with key identifiers (supporting evidence and page reference in transcript – see sample as Appendix 11). At this point, certain themes were de-

prioritised, pending evidence from subsequent transcripts. The remaining interviews were similarly analysed, except that the initial tabling was used as a basis for confirmation, revision and addition to the list of themes and concepts.

Following analysis of all transcripts, I compiled a final table of super-ordinate concepts from across all eight accounts (Appendix 12). Criterion for inclusion within this final table involved not only frequency of occurrence (Appendix 13), but also richness of insight and potential to shed light on other concepts or themes. At this point I shared a summary of overall study's findings and conclusions with participants for their comments. Additionally, my interpretation of interviews was considered by a counselling psychologist with experience of IPA, to enhance my reflexivity. This analysis of transcripts was written up, and the super-ordinate concepts were considered in the light of relevant theory and previous research.

2.9 Transcription

My approach to transcription was influenced heavily by Kvale and Brinkman (2009), who argue that transcription is an interpretative process and thus needs to be explicitly reported. In transforming material from a recording to a written text, researchers need to be aware what material they are including (and excluding), and to what end. As Smith et al (2009) describe, the aim of IPA is primarily to interpret the meaning content of a participant's account, and so a detailed transcription of the prosodic features of an interview such as pauses or non-verbal utterances is not necessary. However, I felt that certain details were necessary in order that an informed linguistic and psychological analysis (see below) could be made. I therefore decided to note incidence and length of pauses, emotional expressions such as crying and laughing and emphases in intonation. Dialectal phrases were transcribed verbatim. All features except emphases were noted in the transcripts by text within square brackets, while emphatic intonation was noted by underlining the relevant text.

2.10 Analysis

Smith et al (2009) propose that the essence of IPA lies in its analytic focus, which is directed towards participants' efforts to make sense of their experience. However, at this stage, I also found it important to remember that, in line with both my epistemological position and with the theoretical underpinnings of IPA, the task of this analysis was not to find one true meaning. Instead, as Kvale and Brinkman (2009) argue, the objective of analysis is to obtain a legitimate and warranted interpretation.

When beginning analysis, there were two main considerations in my efforts to develop this legitimacy of interpretation. The first was to re-confirm what Kvale and Brinkman (2009) describe as my explicit formulation of the research questions to the text. Rather than simply accepting that the stated research questions were my focus, I also sought to increase awareness of personal factors impinging on that focus, through a further period of reflexivity prior to analysis. This involved both autobiographical work and an in-depth review of my insider-outsider status, as well as a new section in my research diary for comments on analytic work.

My second consideration was to decide what process should be used to analyse participants' accounts. Acknowledging the inevitable hermeneutic circle described above, I understood that, as Smith (2007) outlined, the analysis would follow an iterative and inductive cycle: from and between the particular to the shared and the descriptive to the interpretative. While the analytic process was therefore not linear, it was based on the six stages described by Smith et al (2009), which are detailed below.

2.10.1 Reading and re-reading

Choosing to start with a particularly rich account, I aimed to focus my attention on the participant's lifeworld by listening to the audio-recording and by repeated reading of the transcript. Smith et al (2009) suggest this stage can allow the researcher to become more aware of the development of narrative throughout the interview. I noted ideas which arose during this

stage, in an attempt to bracket such understanding until I had completed a detailed review of the participant's account.

2.10.2 Initial noting

During this stage, my aim was to produce a "comprehensive and detailed set of notes and comments on the data" (Smith et al, 2009: 83). In line with suggestions from Smith et al, I began by developing descriptive comments which captured the content of the conversation. I then noted linguistic and conceptual comments; the former considered how content and meaning were presented, and included attention to language use and non-verbal elements, while the latter assessed the participant's implicit and overarching understanding of the matters under discussion. Importantly, these wider and more abstract interpretations remained grounded in the participant's account.

All these exploratory comments were handwritten in the right hand margin of the transcript (see sample transcript as Appendix 10). Descriptive statements were noted in black, with linguistic and conceptual comments in red and green respectively.

2.10.3 Developing emergent themes

Smith et al (2009: 92) indicate that this stage involves producing "a concise and pithy statement of what was important in the various comments attached to a piece of transcript." This required balancing description and interpretation. Although themes emerged located at a particular point in the transcript, their significance within the whole of the account was also considered. Moreover, these themes drew not only on the participant's words but also upon the psychological interpretations of the researcher. I noted these themes in the left hand margin of my transcript.

2.10.4 Searching for connections across emergent themes

My aim at this stage was to map the relationship between emergent themes. In line with suggestions from Smith et al (2009), I explored a number of

alternative connections. Abstraction involved considering whether a number of themes could be subsumed under a new over-arching theme, while subsumption examined whether several themes could be grouped under an existing but more all-encompassing theme. Polarisation involved exploring differences between themes, while contextualisation required considering whether themes linked to particular contextual or narrative aspects of an account. Numeration led me to review the frequency with which themes emerged, while a review of function helped me assess how themes were implicated in the participant's presentation of self.

After this review, I compiled a representation of the three super-ordinate themes which appeared best to represent the meanings within the participant's account (see Appendix 11). Under each super-ordinate theme was recorded supporting themes; these were annotated with page and line references, and a short quote from the participant.

2.10.5 Moving to the next case

I reviewed the first transcript in its entirety before turning to the second account, in line with the idiographic process advised by Smith et al (2009). Stages described in sections 2.10.1 – 2.10.5 were repeated for each successive transcript, whilst I aimed to bracket prior assumptions and do full justice to each particular account.

2.10.6 Looking for patterns across cases

To consider patterns across accounts, I repeated the processes described in 2.10.4, and also reflected on the power of each themes. At this stage, while recognising that frequency alone should not determine significance, I also heeded the caution of Smith et al (2009), that recurrence across cases is important when considering the credibility of findings. Therefore, I decided that a recurrent theme needed to be present in at least half (four) of the accounts, and confirmed the presence of themes systematically through a table of recurrence (Appendix 13). This analysis resulted in an overall table of super-ordinate themes for the group (see Appendix 12), which indicated how themes

were nested within group super-ordinate themes, with evidence from individual participants for each theme.

The full process of the analysis of accounts was then written up.

2.11 Evaluation of research

As Willig (in press) has argued, the criteria used to evaluate research should be consistent with the epistemological stance taken with respect to the data and the researcher's status. Validity (the "truth" or accuracy with which a phenomenon is captured) and reliability (the consistency with which such results can be achieved) are appropriate criteria for assessing research where a straightforward correspondence is assumed between research and an external reality. However, Madill, Jordan and Shirley (2000) suggest that these criteria are problematic when applied to research operating within a critical realist perspective; although there is some sense that data is being 'discovered', there is also an acknowledgement of an inevitable construction through the subjective meanings of participant and researcher. Thus it appeared to me that I had two choices. The first was to adopt the approach of Kvale and Brinkman (2009), and to re-define validity and reliability in the context of my research's epistemological status. However, I rejected this avenue, as I believed that evaluating according to these criteria would have been to operate with concepts ultimately created from a different world view. Therefore I adopted the second approach, which was to evaluate the authority of my interpretation and the utility of my study according to criteria specifically developed for qualitative research conducted outside a naïve realist paradigm.

In this study, I have tried to measure myself against the four qualitative research criteria proposed by Yardley (2000). The first criterion is sensitivity to context. This requires that research is adequately grounded in related theory and in the philosophy of the approach. It also asks that a study be appropriately aware of its socio-cultural setting, with attention given to the norms, ideologies, historical, linguistic and socio-economic influences on beliefs and expectations. Finally, the criterion requires sensitivity to the social context

of the relationship between researcher and participant, and consideration not only of the information given by the participant but the way in which – both generally and specifically – this information has been shaped by the researcher. I have aimed to address these issues in several ways. The Introduction has set out this study's connections to the existing research literature, while the Methodology section has highlighted the theoretical principles underlying the implementation of this research. Clarifying my critical realist perspective, I have sought in the Introduction, Findings and Discussion sections to ensure consideration of relevant socio-cultural influences, as with the examination of the importance of discourses of bodily self-control within the final chapter. This exploration of socio-cultural influences also formed a part of my reflexivity as a researcher; I have aimed to articulate my voice and thinking throughout the research, as well as to explore this issue explicitly within the Methodology and Discussion chapters.

The second criterion raised by Yardley (2000) is commitment and rigour. This requires that the research demonstrates strong engagement with a topic, and competence in the research approach; it also asks for completeness in both data collection and data interpretation. In considering these issues, I have taken a number of actions. In addition to wide reading about cancer in the research and popular literature, I undertook a six month specialist therapeutic training in working with people with cancer. To improve my understanding and skills in interpretative phenomenological work, I attended research seminars and groups where I practised the work of analysis, and read philosophical theory and IPA studies. I ensured that my data collection was complete; the number of participants was appropriate both to the aims of the study and the scope of this work, and the interviews provided the rich, textured accounts necessary for analysis. Finally, in the process of analysis I worked hard to pay attention to the voices of all individual participants, and to ground my comments in data; however, I also developed my interpretation of the phenomenon to a sufficiently deep level, mindful of the pitfall of the too-basic analysis raised by Smith et al (2009).

Transparency and coherence – the third criterion which Yardley (2000) described – is addressed in several ways throughout this study. As laid out

above, I have aimed for a strong fit between the research question and the epistemological perspective and method used in this study. In presenting the analysis and the data, I have detailed all aspects of the collection process in the Methodology section, and provided comprehensive access to data both through tables and samples in Appendices and through frequent excerpts within the Findings, so that the reader can discern relevant patterns. In conducting and writing up this research, I have attempted to disclose key relevant aspects of the research process. This has involved documenting not only concrete issues, such as the recruitment of participants or the procedure, but also non-concrete or reflexive issues, such as my personal motivations for the research, and beliefs impinging on my choices. Lastly, this research has been written in a way that seeks to provide background and support for its choices, and in which issues of methodology and data analysis are addressed thoughtfully, systematically and cogently. However, I recognise that despite my best intentions, an evaluation of this research's persuasiveness can rest only in the hands of its reader.

Yardley (2000) proposed that impact and importance should be the fourth and final criterion for research. One aspect of this is that research offers a new way of understanding a topic, and, as addressed in the Discussion chapter, I believe that my research questions have elicited information which creates significant new information about the wide-ranging change in identities experienced after a breast cancer diagnosis, and about social practices implicated in these changes. Yardley suggests research should strive to make an impact on society and culture, and as described below, this work was conceived with the inherently political objective of documenting the accounts of women's experience, rather than quantifying that experience as a series of disembodied numbers. However, in addition to representation within the research literature, I have already begun to use this study to raise implications for counselling psychology practitioners (Nelson, Smith & Nicolson, 2010); I hope to expand use of this study as a platform to challenge attitudes through more popular media, and as the basis for developing new approaches within my therapeutic work at a cancer centre, thus linking research to practice.

Having explored the way in which I believe this study can be evaluated, I will now address my approach to the ethical issues raised by this work.

2.12 Ethical approach

2.12.1 Conception

The British Psychological Society has outlined ethical principles (BPS, 2006) and guidelines for research (BPS, 2004), which require a researcher to act with care and sensitivity, so as to respect the dignity and psychological wellbeing of participants. However, rather than seeing such issues as a procedural checklist, I have adopted the perspective of Kvale and Brinkman (2009), who argue that ethical issues are embedded in all stages of research. This begins with the conception of the study. I was aware, following feminist researchers such as Hollway (1989), that the production of knowledge is not neutral; my critical realist position involved recognition of the consequences and conditions of power relations in the world which Foucault (1980) has illuminated. Thus in choosing to focus on the experiences of women with breast cancer, I aimed to ensure both that these participants had a beneficial experience of the study, but also that the data gathered in this study would be used to enhance the experience of a wider population of women with breast cancer, through publication in academic and general literature and through translation into counselling psychology practice.

2.12.2 Design & implementation

The design of the study involved several ethical considerations, whose nature I judged particularly important given the psychological impact of a cancer diagnosis. Key among these was the issue of informed consent. In line with recommendations from Tindall (1994), I developed a process where participants were given several opportunities to review their involvement in the research, through both a telephone discussion and also a further email or letter prior to interview. Both telephone and written contact elaborated fully upon what the research would involve, and also possible risks and benefits from

involvement. I believed that this process, which occurred over a time span of three to six weeks, gave appropriate opportunity for informed consent, which was further enhanced by discussion and signing of the consent form on the interview day, prior to starting research. Research was undertaken as outlined in the consent form, and as Kimmel (1988) advises, I made no attempt to mislead participants. Before starting the interview, I made it clear to participants that they could withdraw from the research at any time; to reduce any difficulty over withdrawal, and to lessen the sense of power differential between myself and the participants, no payment was made for interviews. A further ethical consideration at the design stage was the assurance of participant anonymity. Smith et al (2009) argue that confidentiality is not appropriate, as this implies that data will not be seen by others. However, I ensured anonymity of material through the use of pseudonyms in all written documents, while ensuring that any potentially identifiable details (e.g. locations, personal descriptors such as ages and job titles) were modified in any write-up. Consent forms, a master list of pseudonyms and copies of any communication were held in a locked filing cabinet. I maintained transcripts and analysis on a computer with password protection, to which only I had access.

A final consideration in the study design was my duty of care, both towards participants and towards myself. Wortman (1984) and Carter (1993) reported that people with cancer often appreciate the opportunity to clarify their situation through discussion with others, and perceive benefits from doing so. My experience as a trainee counselling psychologist working in a hospice, and my specialist training in working with people with cancer, seemed to equip me to be able to conduct such research sensitively. Furthermore, I hoped that by screening for more severe mental health issues, and through the lengthy consent process, those participants taking part would be likely to benefit from the experience. However, I was aware that participation might result in discomfort, and I addressed this in a number of ways. Firstly, the method asked participants to lead off by raising their own "agenda" of topics, and I prefaced any remaining questions about non-agenda or more sensitive aspects of identity such as sexuality with an acknowledgement that participants may prefer to skip such issues. Secondly, on the two occasions when participants

did exhibit any sign of distress (e.g. tears), I took time to re-confirm whether participants were comfortable continuing with the research. At the end of the interview, all participants received a full debriefing, in line with ethical research guidelines (BPS, 2006). At this point, I explored whether participants had experienced any unforeseen distress, and reminded them that they could contact me or my supervisor if they experienced concerns following the research. All participants were given a resource list containing details of written and personal support, while the location of research within BCH premises meant that - although this option was not needed - connection to therapeutic support was immediately available.

In terms of self-care, I used research supervision to isolate a number of considerations. Research interviews were arranged at the premises of BCH, to avoid any possibility of physical danger. Looking at my emotional resilience, I felt that my participation in a six month specialist cancer training course, in addition to my main counselling psychology training, had enabled me to explore my personal experience of cancer, as well as to immerse myself in the possible aspects of others' experiences. A period of time had also elapsed between my own cancer diagnosis, and the interviews for this research. However, as documented below, I decided to make active use of reflective journals as well as personal therapy, to ensure I was adequately considering my own thoughts and feelings.

2.12.3 Write-up

While the design and implementation of research involved many significant ethical considerations, I was also aware of important ethical issues as I completed the write-up of my study. In addition to anonymity issues, I attempted during transcription to provide an account which respected participants' meanings and remained as grounded as I was able in their original phenomenological experience. Similarly, while going through the process of analysis, I spent many hours dwelling in the data, aiming for the deepest possible penetration of the data, and also to select the most telling excerpts in which the participants could speak forth. In addressing issues raised by Yardley (2000) concerning the transparency of my account and my

reflexivity as a researcher, I was aware of an ethical need to ensure that the research was inspected by others. Kvale and Brinkman (2009) suggest such processes lead to 'verification' and a securer sense of knowledge. Working within a critical realist paradigm, I was aware that there might be different angles on my data interpretation, but hope that others' perspectives would shed light on my position, while also allowing common ground to emerge. Thus my overall research findings were reviewed both by a counselling psychologist with experience in IPA work, and core overall findings were also reviewed by participants themselves. Smith et al (2009) argue that such member validation is not necessary for analysis of a phenomenon, but I felt that a return to participants was appropriate for two reasons: while not taking away my ultimate control as a researcher, it felt like a more democratic exchange, and one which could provide additional perspective on the way I had shaped their experience.

With this in mind, I shall close this Methodology chapter with a discussion on reflexivity.

2.13 Reflexivity

My understanding of reflexivity – awareness of influences on my ideas and actions – has been significantly affected by Finlay (2008). While authors such as Ashworth (1996) argue that these prior understandings need to be separated off to achieve an appropriate and essential sensing of an object, Finlay aligns herself with Wertz (2005), who proposes that researchers' understanding of their experience can enable them to enter and reflect more deeply upon the lived experience of others. In this way, reflexivity is a "dialectical dance" (Finlay, 2008: 3), where past knowledge is both restricted and used to interrogate meanings. This suggests some important characteristics of reflexivity, which became clear to me in the development of this study. Reflexivity is a process; for this study, it began months before starting research with a personal diary and reading during my own experience of breast cancer, and continued throughout the research process in the form of a reflexive journal, reflexive interview, autobiographical work and insider/

outsider status reviews. Reflexivity also seemed to involve openness; openness to my own experience, which enabled me to be open and empathetic towards the otherness of the participant. Finally, I reflected that the nature of this dance meant that my research – as perhaps with any research? – could never account for all the influences shaping it. As Brooks (2008) argues, pre-reflective and non-cognitive understanding of our practices suggest that even explicitly reflexive work is, to some degree, blind.

Therefore an achievable objective was for me to lay out the major ways in which I understood myself to have shaped this research. Wilkinson (1988) provides some helpful distinctions, suggesting that researchers should explore personal, functional and disciplinary factors when assessing reflexivity. Turning to personal features, most obvious is the fact that my own experience of reassessing my identity after breast cancer had prompted my interest in this subject. As Willig (2009) documents in her exploration of cancer, such endeavours can be a way of making sense of the apparently senseless. Bound up in my cancer experience were feelings of surprise and of anger. Gray (2008) suggests our histories are coloured by emotion, which both motivates us and also indicates what is permitted, in public and in private. I was surprised – shocked – to be diagnosed with cancer, when I didn't correspond to any of the 'risk' factors. I was angry, because although the medical care was excellent, the concern for my mental health was negligible. At no point was I asked how the treatment was affecting me, or how I was coping. Luckily for me, I had been able to digest my experience with family and close friends, and to apply my psychological knowledge to interrogate my own understanding. However, I was angry because I felt I should have been asked, and because I believed that many other women would not be in as fortunate a position.

This links to two further personal factors which have shaped this research. My feminist principles meant that, while not driven explicitly by feminist theory, I was concerned to do work which had a relevance to women, and held women as the central focus. My personal experience of cancer treatment suggested that this treatment did not encompass or address the meanings of such treatment for women. While I understand that time and training mean that medical care may not have space to address such issues, I felt that it was

important that these female meanings be adequately represented; furthermore, that a female model of holistic care be set against what has been described as a more masculine model of functional or physical care (e.g. Ussher, 1990). This belief in holistic care was supported by my personal grounding in humanistic ways of working, and a desire to start by valuing the felt experience of the individual human being. Feminist and humanistic factors thus played a part in both my choice of research topic, and also my research methodology and method. A qualitative methodology enabled me to give space to women's voices, and IPA allowed those voices to tell their individual stories. However, I am aware that these choices, while consistent with my critical realist perspective, have inevitably limited the way I can present these identity issues. I chose this method because it was precisely the intersection of the personal with the social which interested me. However, I recognise that this focus on agency risks playing into existing cancer discourses, which, as Willig (2009) describes, blame the victim and position cancer as an individual problem. While considering social practices, this research does not focus entirely on these political issues, and is in that way less emancipatory at a social level. Moreover, my focus on individual lived experience positions this work away from the quantitative research desired for evidence-based practice, thus reducing its political power in a different way.

My perception of my function as a researcher was an important influence on this study. I was aware that my background as a scientist-practitioner gave me a different kind of access to experience from those available to non-psychologist women with cancer. During my own treatment, I was conscious of reading health leaflets not only for content, but also for the positioning and structure which they conveyed: my status as a 'survivor', the stereotypical promotion of femininity through pink bows and pink products. As mentioned above, my fundamental priority was the accurate and respectful engagement with women and their experience. This concern for respectful engagement meant that I was sensitive to my choice of terminology, and the constructive power in language which Willig (2001) describes. One reason for my delight in the revised interview format was that the main 'agenda' was written in the participants' own words. I was careful to follow up and explore their language. When raising more sensitive identities, I chose to use factual labels, such as

“physical body” or “sexual person”. While I recognised that these were clumsy, the labels seemed to allow access to the areas of experience I was hoping to explore, and were not as jargon-ridden as alternatives such as “embodied person”. However, although mindful in my local use of language, I rejected the excessively critical stance towards academic discourse which Langdridge (2007) discusses. Instead, I sided with Gough (2003), who suggests that extreme concern over the expert position of the researcher is self-indulgent. Drawing on my own experience, I believed that my professional background meant that I would be able to add additional perspective to the accounts given by the women in my study, and that IPA would enable me to create a more useful, multi-layered interpretation of this phenomenon.

My particular personal-professional position led to further considerations of function. Le Gallais (2008) has reflected on her own dual insider-outsider status in research, and this threw light on my own experience. In many ways I saw – and indeed positioned – myself as an insider, due to my own experience with cancer. This was an advantage, in that I was familiar with the breast cancer terminology and sensitive to nuances, such as the feelings felt when viewing your body after surgery. After much reflection, I chose to disclose my own experience, but at the recruitment stage only. I hoped that nature and timing of this disclosure would reassure women of my commitment to the research and help to build rapport, while keeping the focus on the women’s experience at the interview stage; this seemed to be borne out by participants’ feedback after the interviews. However, I was also mindful of the dangers of this insider status. Over-identifying with the participant group as a whole, or with particular views, could reduce the sharpness of my insights. It might mean that I failed to explore difference, and result in the shoddy interpretation which Kvale and Brinkman (2009) deride. In summary, while feeling a strong ‘kinship’ with participants throughout this study, I was conscious of my over-arching duties as a researcher, and ultimately my outsider status as the interpreter of their experience. My experience was usefully captured by the research commentary from Mama (1987, quoted in Hollway, 1989:130); talking about being multiply positioned, she asserted that it enabled her to “abstract myself enough to be able to identify with discourses, yet empathise enough to recognise them and identify with participants”.

This brings me to my final area of concern in reflexivity: disciplinary issues. This required me to consider the stance which I hold regarding the status of phenomena, my position as a researcher, and the ultimate political purpose of my research: "with what voice, to what end, using what criteria" (Kvale & Brinkman, 2009: 272). While the status of phenomena and researcher have been addressed in earlier sections, I would like to conclude this Methodology chapter with a consideration of this "end". From the beginning of this research, I have seen it as exemplifying the potential of counselling psychology at many levels. At a micro level, my use of self which I developed as a trainee counselling psychologist enabled both the instigation of this research, and also its implementation in ways which, as I shall discuss later, were described by participants as useful and meaningful for them. On another level, I see this study as fitting with counselling psychology's challenge to normative patterns of thinking, and in particular its critique of tyranny of the medical model, as described by Strawbridge and Woolfe (2003). Medical procedures often ignore the individual experience, the social context, and the psychological impact of treatment. This research aims, in its own small way, to redress that issue with regard to younger women's experience of breast cancer. Lastly, while this is not action research, I have always been mindful of using this study to inform my ongoing counselling psychology practice with people with cancer. Since starting this research, I have already been able to establish a specialist therapeutic group for younger women with cancer, at the centre where I work. I hope, again in some small ways, to continue making sense of my experience by being better able to help those coming after me.

3 Analysis

I define who I am by defining where I speak from, in the family tree, in social place, in the geography of social statuses and function, in my intimate relations to the ones I love, and also crucially in the space of moral and spiritual orientation within which my most important defining relations are carried out. (Taylor, 1989: 35)

3.1 Overview

Before delving into the detail of the analysis, I would like to provide some background as to the principled choices and overall structure of the material presented.

3.1.1 Principles guiding analysis

In this chapter, I have sought rigorously and honestly to convey the perceptual content of participants' accounts. This has been attempted through selection of material which is both representative of the core experiences of the participant group, and which also ensures a voice for each member of the group within the full analysis. In some themes, the phenomenon appears best represented by a wider range of accounts which capture the different colours of experience; in other themes, I have chosen to follow up a narrower range of quotations whose richness of language or perception cast particular insight. As a supplement to these instances, a full set of quotes for each theme is included within the table of super-ordinate themes (Appendix 12).

In writing up this analysis, I decided to exclude theoretical literature as I felt this would direct attention too far away from the lived experience. I have chosen instead to focus on interpreting the detail of participants' accounts, and the links between these accounts. Importantly, while aiming for a legitimate presentation of a phenomenon, I have also tried to preserve some holistic

integrity in women's accounts, through consideration of personal interconnections between themes. These considerations form the basis for my interpretation of participants' interviews, thereby creating the multi-layered exploration of meaning or "double hermeneutic" (Smith & Osborn, 2003) which is the objective of IPA.

3.1.2 Overall organisation of analysis

Use of the "Who Am I?" (WAI) sheet resulted in a large amount of vivid and relevant material, and I am grateful to my participants for their commitment to detailed description, and for allowing me insight into emotionally significant issues. One advantage of the initially un-structured WAI tool is that it allowed participants to convey their own sense of identities, free from potential constraints of psychological framing which an interviewer might have brought. Thus I feel that the representation of identities outlined below describes a phenomenon which is at once broader and more intricate than the one which I had envisaged at the start of this study. When analysing this material, I maintained my focus on the key research aims of understanding continuity and change in the content of identities after breast cancer, and illumination of positive, problematic and salient aspects of such identities.

My analysis resulted in three super-ordinate themes, which represent the content of identities which participants described experiencing after breast cancer. Amongst my participant group, six of the eight women described experiencing significant overall change in identities, while two women felt they had generally undergone only modest change. However, within the different themes, the extent and nature of change varied considerably. Despite the wide-ranging nature of the subject, I found that these three super-ordinate themes were able to contain the range of individual experiences across the group. In creating these themes, I have aimed to hold the tension between being sufficiently psychological and interpretative, whilst also maintaining connection with participants' words. This is encapsulated in the titles of the three super-ordinate themes, which marry psychological language with quotations from participants. The majority of subordinate theme titles are also drawn from women's accounts.

While each theme addresses particular areas concerning the content of participants' identities, there are – as so often with IPA – intimate and intricate relationships between the themes. These are briefly drawn in Table 3.1 below, and outlined in greater detail within the analysis and in the closing section of this chapter. "Challenges to embodiment: The body does its own thing" explores how perceptions of, and changes to, the body can have profound implications both for participants' overall sense of self and for particular identities. "Negotiated roles: What are you looking for now?" describes participants' experience of change in their social roles following their diagnosis with breast cancer. This includes the re-evaluation of previous roles, and the consideration of new roles arising from their cancer experiences. The final theme is "Emotional-existential dilemmas: Re-learning what life's all about". While grounded and connected to the particularities of the first two themes, this final theme comprises more global issues of identity relating to mortality, autonomy and meaning.

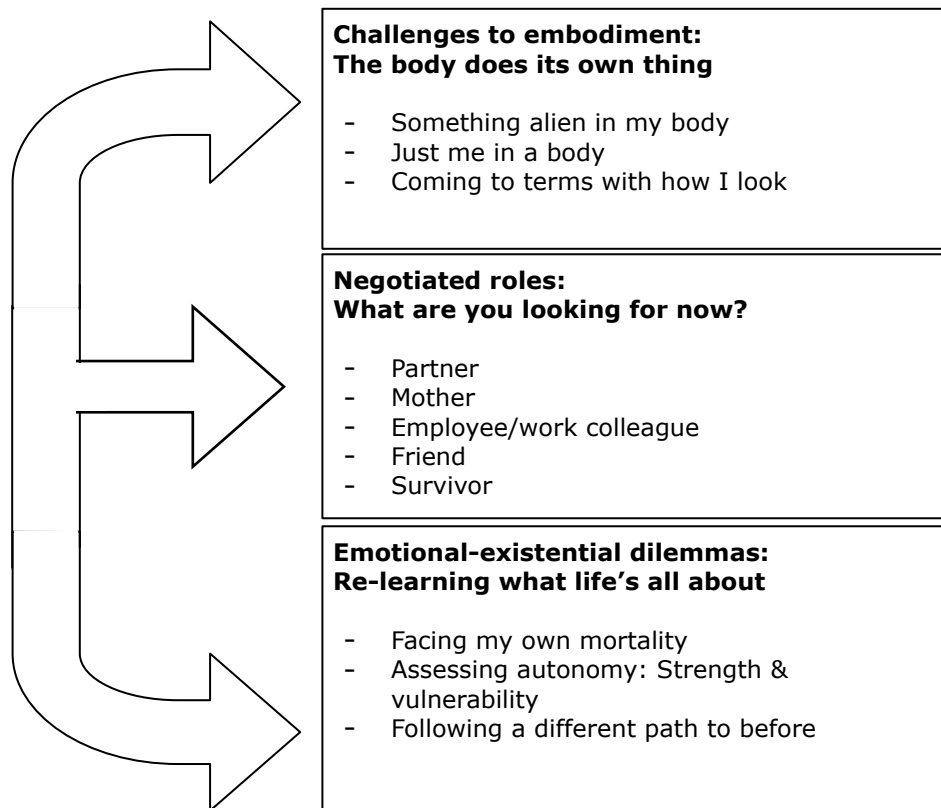


Figure 3.1 Representation of Super-ordinate Themes

3.2 Challenges to embodiment: The body does its own thing

This super-ordinate theme captures how breast cancer led the participants to become more aware of their physical state, as they were asked to reassess previous embodied identities and wrestle with new issues of embodiment. Within the super-ordinate theme fall three different themes. "Something alien in my body" considers how breast cancer triggered new experiences of the body as out of control, repugnant and - ultimately - stigmatised. "Just me in a body" addresses participants' experience of a shift in the understanding of, and relationship between, their body and their sense of self, both during and after cancer treatment. Lastly, "Coming to terms with how I look" explores how breast cancer affected these women's sense of their appearance, and the resulting impact on different aspects of their identity.

3.2.1 Something alien in my body

The diagnosis of breast cancer – the paradox of a potentially fatal disease in a part of the body associated with nurturing life – asked participants to make sense of this situation within their bodies. For Ursula, as for many participants, the response was to construe the cancer as something alien.

It did feel odd at one point that there had been something alien in my body...which sounds a bit weird. That did feel strange. [..]

(I) There was a sense of something happening in you?

[Ursula makes sudden roaring scary monster sound, and moves as if to pounce with her arms]

[..] So it did feel odd, especially since he said it had probably been there for a year.

(I) That feeling of having something inside you which was working against you, almost?

Yeah, yeah. The enemy within...

(Ursula: 7,4-10)

Ursula's perception of her cancer as "alien" can be understood on many levels. The cancer is alien in that it is foreign to her body, an objectified "it" or a separate "something". However, in Ursula's dramatic non-verbal enactment of cancer, it also seems to take on the frightening form of an alien being from another world, almost as if a creature from myth. Furthermore, Ursula suggests how this shape-shifting cancer can be experienced as alien by being conceived as a malign agent, working against the "state" of the body ("the enemy within"). In these ways, breast cancer appears to be positioned as something other than the body, which has its own force and agency. There appears to be a sense of the body being engaged in a war with a hostile force, and this is echoed in other participants' accounts. Becky describes the horror of breast cancer as being like "a foreign invasion in your body" (29,6), while Lesley also recalls the terror of finding "something alien" (4,6).

This sense of an active, alien presence in the body is not restricted to diagnosis, but can be experienced after treatment has been completed.

And if I'm sat in the car, to get out of the car sometimes it hurts. Then you see I'll start to worry then, maybe it's more than that, maybe it's moving and it's in me bones. It's just a constant worry all the time. (Zoe: 10,21)

Despite having completed chemotherapy and radiotherapy, Zoe describes how she anxiously wonders whether new sensations in her body may be caused by the spread of breast cancer. Again, cancer is construed as something separate from the body, with its own agency ("maybe it's moving"). It appears that this construal of the cancer is associated with a lack of trust in her body, which is seen as harbouring something dangerous. However, this sense of something alien is not limited to the cancer. The treatments for breast cancer can cause women to experience their bodies as something tainted.

Physically, I felt contaminated. I felt like I'd got some, well, I know it's like poison. I just felt I didn't want me kids to kiss me. I just felt....horrible, that's from the actual drugs going in. (Zoe: 37,10)

In her use of the word “contaminated”, Zoe indicates how she sees her body as polluted by chemotherapy. The intensity of her perception is reinforced by the subsequent simile which likens the drugs to poison, something which destroys life. Zoe’s sense of contamination is so strong that she does not want to kiss her children, possibly from a fear that she will endanger them. Thus this sense of being a contaminated body requires Zoe to separate herself from others, as if she is someone with a dangerous and stigmatised condition.

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— Louise’s account extends our understanding of the ways in which breast cancer treatment can lead to disconnection from the body and a sense of the body becoming alien.

This awful drug they put in me made all my hair [...] it was kind of coming off. And I remember waking up one day and it was in my mouth, it fell off in my sleep and it was in my mouth...[...] Going in the shower and literally you’ve had to take clumps of hair out the plug hole. And it’s like nobody, it’s like that was part of, your hair is part of your identity, isn’t it? (Louise: 5-15)

Louise begins by describing “my hair”, but as the chemotherapy causes her hair to come out, she turns to using the impersonal pronoun “it”, perhaps suggesting the transition from something which belongs to her to something alien or disconnected from her. Moreover, the shift from use of the personal pronoun (“my hair”) to use of the second person position (“you’ve had”) might be seen as a further disconnection, which in some ways protects from the emotional distress of witnessing parts of your body fall away. In the last line, it appears that she is wrestling with the nature of changes to her embodied identity. Louise begins by construing the association between hair and identity in the past tense, but then rephrases this, as if to assert its continuing importance. This temporal uncertainty might be seen as reflecting Louise’s challenge in understanding what does indeed constitute her physical identity.

The challenge of dealing with something alien can extend beyond treatment and diagnosis. Nina chose an augmented reconstruction as part of her treatment for breast cancer, but this left her dealing with mixed feelings about her breasts.

Um the boobs, um, they're complicated, in that, um, the one I had the mastectomy on, then had the tissue from my tummy put inside it, and, um, I can't feel it. So although it's physically there, I do find it kind of weird in that [...] they never really feel like your own any more. [...] I have felt in the past that they belonged more to my doctor than they did to me. (Nina: 38,14-24)

As with earlier participants, Nina uses impersonal language which appears to distance herself from her breasts ("the boobs"; "they"). However, she also describes another kind of separation from her body, which derives from her experience of not having any sensation in her reconstructed breast. For Nina, the weirdness traces to that fact that her breasts "never really feel like your own any more", but she goes on to elucidate a double meaning in the word "feel". It is not only that she cannot experience sensation in her breast, but also that she perceives that her re-constructed breasts are no longer part of her, but rather belong to her doctors. In this sense, she appears to be questioning the integrity of her embodied identity, and whether this new body is fully her own.

Finally, although almost all women described some sense of alienation from their bodies, Rachel commented on her awareness that she had not experienced this change. Instead, she observed what appeared to be an absence of resentment towards her body:

I didn't feel a way about my body you know like as in... my body has done this to me, it's developed cancer. (Rachel: 19, 21)

In her interview, Rachel mentioned that she had experienced eating disorders in her twenties. While on one level this might have been considered to increase her vulnerability to body issues, I hypothesise that Rachel's previous engagement with questions of embodiment may have left her with a pragmatic accommodation to her physical state. This accommodation appears to be echoed in a later embodied identity relating to appearance.

In summary, this theme has explored how breast cancer led most women to a new and disturbing experience of their bodies as something alien. This alien

quality can be seen to take many forms: a frightening monster or bogeyman; a malign and cunning agent; something which is contaminated and impure; previously integral things which are now disconnected or the property of someone else. Furthermore, this sense of something alien is experienced not only in connection with the cancer, but also with many aspects of the body. In various ways, therefore, these experiences appear to be prompting women to consider to what extent they can control and trust their bodies, and to what degree they perceive these bodies to be part of, or something separate to, their sense of self. This question is amplified in the second theme.

3.2.2 Just me in a body

This theme explores how treatment for breast cancer affects women's understanding of the relationship between their sense of self and their bodies. Throughout these accounts, there appeared to be a constant questioning of the relationship between physical condition and mental states:

...now I honestly feel some days that I'm just me in a body and I just get from A to B like a bod, you know, like a, like as if, I'm almost just, not shut off emotionally [...] but I just um my whole life at the moment is just cancer, cancer, drug taking, um, battling, on my mind all I think about is trying to lose the weight, trying to get my life back. (Louise: 19,32)

My understanding here is that Louise perceives herself to have been reduced to operating at the level of a "bod": a quasi-mechanical creature whose existence involves moving from one physical cancer issue to another. The repetition and use of lists ("cancer, cancer, drug taking..") indicates both the relentless nature of this physical struggle and its domination of her existence, to the point where she feels other aspects of her functioning - such as her emotions - are almost closed down. Louise describes herself as engaged in battle for her life; whilst this can be interpreted on one level as a fight for survival, her earlier comments ("just me in a body") suggest that getting her life back may also mean a return to an existence where preserving her physical state does not take over her whole life. The use of military imagery here, and throughout many descriptions of cancer identities, indicates that participants find such

discourses useful in capturing the intense struggle for life, and also perhaps the sense of separation between the mind and a body occupied by the enemy cancer.

Zoe's understanding of her experience indicates how breast cancer can subvert women's usual chronological sense of their bodies, thereby throwing mental constructions of identity into flux.

I feel, physically I feel older, coz I feel absolutely shattered and worn out and like an old woman sometimes. I seem to ache all over, which I know is the after-effects of the treatment and will improve, but I just feel...feel older in meself. (Zoe: 7,20)

Many participants talked of the overwhelming exhaustion and fatigue caused by their breast cancer treatment. In her interview, Zoe described how happy she had been with her body before her cancer diagnosis; she perceived herself to have been fit, toned and outwardly healthy. In stark contrast, she outlines here how physically she feels used up ("worn out") and is constantly in pain. While Zoe describes "knowing" that her physical state is linked to her treatment, she repeatedly asserts how she "feels" or experiences her condition as similar to that of an old woman: an apparent dissonance between her cognitive and phenomenological states, or at least between her interpretations of her sensations. Although Zoe is less than forty years old, her physical state appears to have catapulted her into a different life stage, that of an "old woman". As we will explore later, Zoe's sense of feeling older relates not only to her physical experience, but also to her mental experience.

Louise and Zoe were both prescribed the full range of breast cancer treatments – surgery, chemotherapy and radiotherapy – and therefore might be considered to have undergone the most severe physical experiences. However, the accounts of those receiving less extensive treatment also indicate that a change in the perception of the body's capabilities is associated with a change in self.

I still get pain from the areas around about the operation, there's still scar tissue there and obviously I still have the hot flushes, um, I sometimes feel tireder than I

did previously.[..] I had the opportunity to go skiing earlier this year and I called it off [..] because I was frightened that someone would bang into me or I would fall or hurt myself. So that kind of dare-devil streak, that's gone, to be replaced with a bit more of a measured um assessment of my physical capabilities. (Becky: 27,1-13)

Becky underwent surgery and radiotherapy to treat breast cancer, and is now taking Tamoxifen medication with the aim of preventing recurrence. In her comments here, the juxtaposition of statements about ongoing physical symptoms with her fears for her safety while skiing suggests that breast cancer has created a new sense of the limitations and frailty of her body, which she did not previously hold. Becky's description of the loss of this care-free, "dare-devil streak" indicates how she sees her identity to have been re-shaped by her new, more "measured" understanding of her body.

While this changing relationship between body and self was more frequently perceived as negative, there were certain participants who experienced either minimal change or a more enabling relationship. Lesley had had many serious – and at times, life-threatening – physical conditions before she was diagnosed with breast cancer. She describes how having breast cancer caused her to transform her understanding of her physical condition, and ultimately of her self.

Till that time...that I got breast cancer and came through everything, I just thought I was a very weak person physically.[..] But I have turned that on the head now and I believe that I am strong because I have come through all these things [..] maybe I'm not as strong as some others lifting things and whatever, but I do believe I'm strong because if I wasn't strong after having all these experiences I have had, I wouldn't be here. (Lesley: 2,24-3,7)

Lesley's account suggest that, rather than viewing breast cancer as a further sign of physical weakness, she instead developed a belief that coming through these multiple physical issues was an indication of her strength. She carefully delineates between different aspects of strength, seeing her own as relating not to day-to-day measures such as lifting weights but rather to her capacity to stay alive. As will be discussed later, Lesley goes on to relate this physical resilience to her understanding of mortality, and also to the overall meaning

which she perceives in her ongoing existence. While these issues are not explicitly mentioned here, the repetition of the word “strong” can perhaps be seen to convey significance beyond the simple description of a physical state.

Drawing together the varying aspects of this theme, it appears that participants’ experience of breast cancer prompted a re-appraisal of their embodied state, and the way in which mental states are contingent upon this embodiment. It is also clear that participants perceived this embodiment to be the foundation for their ability to engage with a broader range of life activities, and thus the taking-up of other identities. Within the theme of “Just me in a body”, this re-appraisal of the embodied state has been restricted to perceptions of the physical condition or “running capabilities” of the body. However, in the final theme in this section, attention moves to participants’ awareness of how the appearance of their bodies shapes available identities.

3.2.3 Coming to terms with how I look

It is perhaps unsurprising that breast cancer led all participants to an assessment of their appearance. All experienced at least some modification of their bodies, through surgery, radiotherapy or chemotherapy. In their accounts, each woman’s sense of these changes appeared to be mediated both by her previous sense of their body, and by her new perceptions of her body within the wider social context. These assessments resulted in an evaluation of the new status of their body, as implied by their appearance.

Both Gilly and Rachel underwent reconstructed mastectomies as part of their treatment for breast cancer. They relate their sense of how earlier embodied identities interacted with interpretation of their body’s appearance after surgery. Gilly described her satisfaction with her altered body, but also went on to ground this change in the wider meaning of breasts for her embodied identity.

Obviously, he’s done a fantastic job, the breast surgeon, so um and I could wear a bikini, you’d never know, except for my back, the scar on my back... (Gilly: 42,7)

I've never had you know fabulous boobs so it wasn't my asset [...] I can see to some women you know it would be you know, I never liked mine or had a great love affair with them [laughs]. (Gilly: 45,1)

Gilly appears pleased with the appearance of her body after surgery. She measures the surgeon's "fantastic job" by the way her breast reconstruction is barely apparent, even in a bikini: something she alludes to elsewhere as "my little secret" (40,13). Gilly's comments suggest that one way of satisfactorily coming to terms with a new appearance is through the preservation of a public face, where no change can be discerned by others. However Gilly's account also indicates how her previous attitude towards her breasts may have influenced this evaluation. Gilly construes "fabulous boobs" as an "asset", something which possesses useful qualities, which in this case may presumably relate to social presentation or the attraction of partners. From her comments, and my sense of her seemingly pragmatic laughter, I inferred that her breasts were not a central part of her positive evaluation of her embodied identity before her experience with breast cancer, and thus perhaps that her subsequent altered body has been easier to accept.

Rachel appears less positive than Gilly in her assessment of her new appearance. Despite this, she indicates this assessment has affected her less than she had feared.

I think I thought it would be worse, it's not as bad as I thought it was, I mean I go through, it's funny, I go through like phases of being really upset still about it, thinking oh even if, even when the reconstruction's done this one's still actually generally going to sit down here and this one's going to be, you know, round and sit right up here, and... (Rachel: 17,16)

Discussing a previous "fractious relationship" (16,13) with her body which included disordered eating, she indicates that, although upset with the differing appearance of her two breasts, she has not yet experienced the "total disgust" (18,20) with her body which she had felt in earlier situations, and had worried might occur again. It is possible this may trace to the fact that her reconstruction was ongoing at the time of interview, and therefore she was

hopeful of future improvement. It may alternatively trace to a strategy of “putting things aside” (20,25), to which Rachel alluded in our discussions.

Nina’s account also demonstrates how earlier evaluations of embodied appearance interact in complex ways with post-cancer assessments of physical looks. As well as the reconstruction following a mastectomy, Nina chose to have her breasts enlarged.

Because I’ve had a boob job, I do feel more feminine. It does feel really nice to have boobs for the first time in my life that are quite presentable, you know, they’re two or three times the size of the ones before.[..] Um, it’s just the scars, you know. (Nina: 40,18)

Although mindful of the scars, Nina seems generally to perceive her new appearance to be an improvement on her previous, pre-cancer body. She takes pleasure in the larger size of her breasts, which she associates with a sense of greater femininity, potentially through her sense of better fulfilling social criteria for womanhood. This appears to have given her greater confidence in her appearance; by being more “presentable”, it seems that both she - and others? - judge her body as better equipped to perform her gendered role as woman.

While some participants’ evaluation of their appearance seems to involve acceptance of and accommodation to the surrounding social context, Louise is notable for her analysis of how her personal evaluation of her appearance is made problematic by wider social values. Using stark and extreme verbs, she describes initially the intense hatred and shame she feels for her new appearance.

I’m just I’m disgusted with my body now. I hate it. I look in the mirror and I hate it. I don’t recognise myself at all. I hate it and I just, it wouldn’t be so bad with the chemo [...] but with the Tamoxifen, it’s for five years, it’s almost like having to come to terms which I haven’t yet that this could be my body for five years! (Louise: 7,2)

Louise is frank in her rejection of her appearance: she does not recognise this new embodiment as representing her self. She indicates how the altered

appearance which has resulted from her cancer treatment has provided her with an alternative, unwanted and (implicitly) devalued identity as a cancer patient.

...while I've got the headscarf on, the weight gain and all around the middle, the spongy chemo weight, I look like a cancer patient and I don't want to be a cancer patient any more. (Louise: 52,4)

Louise goes on to explain how cancer can not only lead to implication in less attractive or desirable identities, but can also make it harder to comply with social regimes and standards for appearance.

..it is this whole media thing now of perfection. And if you haven't got perfection in today's society [...] you can pay for perfection. And everybody aims for this perfection coz it tells you you have to be. So when you've got something wrong with you that's out of your control, you know that you're kind of one step behind everybody else. (Louise: 17,25)

In this excerpt, Louise appears to suggest that in the cultural context of UK society, "perfection" of appearance is not only desirable but morally required; that not to have a certain look is a stain on character ("you have to be"). Moreover, the phrase "one step behind everyone else" indicates how Louise feels that impact of cancer treatment on her appearance has left her socially disadvantaged, and as we will explore later, she explicitly associates this with the competitive search for a partner.

However, Lesley's account suggests that there are different social discourses on appearance, and these may be variously employed in the service of different embodied identities.

I've never liked my body [...] maybe at one time I might have thought about having liposuction or botox or whatever and I think they are such idiots and fools now, you know, in the respect of you do not mess with nature, you don't know what you're going to get yourself into [...]. You have to accept how you are and make the best of yourself [...] and ...therefore, embrace yourself. (Lesley: 6,15-27)

Lesley indicates that, prior to cancer, she was dissatisfied with her appearance, and would have considered social practices such as cosmetic surgery which she felt would enhance her body. Yet following her experience with cancer, she seems to have greater respect – and perhaps also some element of fear? – for the natural state of her body (“you do not mess with nature”), which may link to Lesley’s new sense of her body’s strength, as discussed in section 3.2.2. As part of this change, Lesley’s account suggests she has taken on different social discourses, which lead her to be more accepting of her appearance.

Throughout these quoted examples, participants have indicated the extent to which breast cancer has involved a – largely negative - reassessment of their body’s appearance and “visual” identity. It is worth noting that comments about this visual embodied identity emerged spontaneously from participants; while they are obviously connected to particular role identities such as “woman” or “cancer patient”, they also in many cases stand independently from these roles. These women’s accounts suggest that such body images or identities are influenced by body images held before diagnosis with cancer, the degree of physical change resulting from cancer treatment, and by social discourses relating both to women’s bodies and to cancer.

In this first super-ordinate theme, then, I have considered how women experienced changes in their embodied identities. These experiences included perceptions of the body as alien, and a sense of the body as fundamental to – and controlling of – other identities. Participants’ accounts also suggest an awareness of the appearance of the body not only as representing one’s self, but also as an indicator of moral and social worth, and as a facilitator of other identities. This leads us to the second super-ordinate theme.

3.3 Negotiated roles: What are you looking for now?

The second super-ordinate theme encompasses those role identities which held significance for participants after their experience with breast cancer. The identities could be considered as dividing into two camps: role identities present in participants’ lives prior to cancer, and new role identities thrown up

by cancer. Word-count limitations mean that I have had to curtail the number of roles represented. Within this thesis, I will cover the re-evaluation of the previously held identities of partner, mother, friend and employee/work colleague, and also consideration of the new identity of cancer survivor. Identities mentioned by participants but omitted here are those of daughter, woman, sexual being and patient. When considering which roles to include within this thesis, I chose to include those which had the widest representation across participants, and roles which I judged to have the richest descriptive material and greatest salience or spontaneity of recall for participants. As with the previous super-ordinate theme, my analytic focus was on participants' experience of continuity and change in these identities. Due to the varied experiences of participants within each identity, I have chosen to use simple role descriptors, as I struggled to find one participant's words which would adequately stand for the group.

3.3.1 Partner

With one exception, all participants appeared to feel that their experience with breast cancer had raised the importance of this identity. This was the case, whether participants were currently single (five women) or in a committed relationship (three women). While coping with unfamiliar experience of breast cancer, Zoe seemed to find her marriage an importance source of stability: a quality captured in her description of her husband Jamie as a "rock" (15,12). Zoe perceived that cancer had changed her nature of her marriage.

He's just carried everything and carried on [...] Five, six years ago, I didn't probably open up to Jamie. I didn't feel like I needed him, for me, you know, but I certainly do now. I mean, it's, that's, I suppose that's a good thing to come out of this, we're closer, and I think we've got ...we've got to a different level really. (Zoe: 17,34-18,8)

Zoe appears to value Jamie not only for the general support he offered ("he's just carried everything") but also for the emotional support which he provided to her. Zoe contrasts her previous emotional self-sufficiency and lack of openness with Jamie with her sense of greater personal vulnerability following

cancer, which she sees as having enabled her to reach a different level of emotional intimacy.

Lesley and Nina's accounts also describe how they became closer to their husbands. However, in Lesley's experience, this change in identity traced not to a sense of vulnerability but to the realisation of "how much he loved me and wanted to protect me" (46,21). As with Zoe, Lesley perceived this support to have been expressed in both emotional and practical ways.

He did everything he possibly could [...] That first night after being diagnosed [...] I just laid in his arms all night crying and being emotional [...] He was there with me every step of the way, you know. Every specialist treatment I had, even now he comes and sees the specialist with me... (Lesley: 46,22-31)

As in Zoe's account, the value which Lesley places on the relationship seems to stem in part from the ability to express emotional distress at moments of existential crisis, such as the first night after diagnosis mentioned here. From the use of singular pronouns such as "I" and "he", I hypothesise that Lesley was still aware at this time of an existential difference between her condition and that of her husband. However, she appears to have drawn comfort from the constant and ongoing support which her husband offered. This contrasted with the experience of Nina, where despite a sense that cancer initially "did bring us together" (16,34), she perceived a decline in intimacy and attention over time.

He's entitled to his own life but it does consume a lot of his thoughts and you know...I think I feel a bit forgotten sometimes. (Nina: 20,23)

While Nina seems to continue to place a high value on such attention and intimacy, the description of her husband's behaviour suggests he may now not accord these qualities the importance he did earlier in the cancer experience. In using the word "forgotten", I speculate that Nina may feel that her partner has moved on from the cancer experience and this different connection with his wife, while she herself feels that this experience requires longer and more sustained recognition within their relationship.

Among those participants who were single, there appeared to be an equally high importance placed upon relationships both before and after cancer. However, participants were now much more pessimistic about their chances of achieving such a relationship.

I couldn't even find a boyfriend when I had a fully, you know when I had an ordinary body and now I've got, you know, it's going to be even worse...(Rachel: 37,17)

Rachel links her belief in her reduced chance of a relationship to the loss of an "ordinary" body: a body that has got something which she cannot bring herself to name ("and now I've got"). This shadowy sense of the stigma of cancer compounds earlier concerns Rachel had had about forming a relationship.

It attaches itself to my old...things [...] it's a more tangible reason why I'm right that I will always be on my own, and now I've got proof in a way. (Rachel: 38,4)

The phrase "I've got proof" might be interpreted on one level as conveying the greater difficulty in starting a relationship, within a society which views cancer as dangerous and undesirable. However, I wondered whether Rachel hinted at another level of meaning: that cancer was a moral judgement which implied proof of some lesser value in her self. Yet in one regard, Rachel sees that cancer might help her realise this identity as a partner, by being an efficient screening tool for the kind of man she is looking for.

I can say well actually...I've had cancer and had a mastectomy so [...] if they stick around [...] they're interested, actually interested in me as a person rather than the physical body... (Rachel: 39,30-40,3)

Here, Rachel appears to suggest that stigmatising social conceptions of cancer may act in her favour. Her new embodied condition will act as a way of discriminating between men who choose relationships purely on physical criteria rather than on an attraction to the whole person. However, like her fellow participant Louise, who describes her single state as a "life

sentence" (15,6), Rachel seems to be pessimistic about her chances of achieving such a relationship.

Looking at how our animal instincts of survival of the fittest, are you necessarily going to pick somebody who's had a life-threatening disease? (Rachel: 42,16)

Echoing Louise's earlier views on appearance and embodiment, Rachel appears here to see herself existing in a world where she is competing against others to be selected for a relationship. Her experience with cancer is a Darwinian stigmata, a sign of weakness which compromises her ability to achieve the identity she desires.

Within the participant group, Becky is notable for the reduced importance she now places on a relationship.

...for the first time in my life I really do not want to be in a relationship [...] ...if it happens, it happens, if it doesn't, that's fine as well. Um but that kind of contentment is directly a result I think of the cancer and of realising that, you know, life is there to be enjoyed and it's down to you to make it enjoyable, not somebody else. (Becky: 30,4-23)

Having come out of a long-term relationship shortly before being diagnosed with breast cancer, Becky describes here how she now feels less need to be in a relationship. She attributes this directly to her experience with cancer, and a new sense of her own capacity and responsibility to supply her own enjoyment. This links to an aspect in the final super-ordinate theme, which is Becky's awareness of her personal autonomy.

In summary, the role identity of partner appears to have increased or maintained its significance for the majority of participants. Only one woman perceived the partner role to be of lesser importance than before cancer, and this related to an existential re-assessment of the support which should be derived from others and from oneself. Those women in relationships appeared to place greater value on the role, through the appreciation of the emotional and practical support which they received during their experience with cancer. However, for those women who were not in relationships before their breast

cancer diagnosis, there is no change to the value they place on this identity, but rather a bleak assessment of their chances of achieving it. These women's accounts suggest they perceive their "marketability" has been reduced by the stigma attached to cancer.

3.3.2 Mother

All participants experienced some degree of change in their actual or potential identity as a mother. In some ways, this change was experienced as enabling. Ursula was unusual in her relief that, as a woman without children, she was spared the emotional distress she felt this might bring.

Because I haven't got children, it makes a huge difference ..[...] that must be awful.
(Ursula: 19.20)

For those like Gilly who were mothers before being diagnosed, having children was seen as a fundamental source of strength.

They give me purpose at the moment, you know, they make, I know they still need me.
(Gilly: 7,25)

It is this concern for her children which Gilly perceives to motivate her to persist with another identity, that of an employee, despite the overwhelming exhaustion she experiences after cancer treatment.

I think that's what drives me to work and keep everything going because I want you know my daughter's learning to drive, she's at a private school [...] you need all these, I want them to have things. (Gilly: 12,30).

However, mostly women who were mothers described a difficult struggle to protect their children from the emotional and practical consequences of their breast cancer. Nina summarised the efforts of many mothers, when she talked of organising things so that "my husband would have as normal a life as he could, and the kids could go on going to school normally" (6,30). Yet the

severity of different cancer treatments and availability of care meant that it was not always possible to preserve this normality, as Zoe describes.

I just did what I could...but for the first week or whatever I was just sort of in bed and being ill, and I know I couldn't help it but I still felt guilty, because the kids still need you, don't they? I mean, they're innocent, aren't they, they're just, they need their mum. (Zoe: 2,29)

Zoe's account suggests how her physical condition makes it hard to be the mum she wants to be. But her words also indicate how she feels guilty for her failure to fulfil this role, even though she understands that she has not chosen to have cancer. This juxtaposition of her guilt as a mother with the innocence of her children might be interpreted as connecting to the previously mentioned description of herself as "contaminated": that the stigma of cancer can itself contaminate role identities central to the self. Cancer appears to be experienced not only as a social judgement, but also as a personal moral judgement of the self.

This struggle to protect children extends from day-to-day routines to deeper issues of physical and emotional welfare. The incidence of breast cancer in Zoe's family led her to fear a genetic cause, which might affect her daughters as well as herself.

See, you want to protect your children, and I do everything I can, you know, but this is out of my hands, it's...That's hard to deal with, that. It's like a clock ticking away. (Zoe: 5,19)

Despite everything Zoe does, Zoe indicates how breast cancer has highlighted her ultimate impotence as a mother to protect her children. Her image of a clock ticking away brings to mind the sense of time being counted down, or possibly a time-bomb waiting to explode, and is one of many similar images in her interview ("turn back the clock", 4,24; "the clock was ticking", 12,28). It suggests that cancer has confronted her aspirations as a mother with the limitations of the physical reality of the human body, and the existential nature of human existence. These physical realities also preoccupy Lesley, who

describes how she perceives it to be part of her role as mother to make her children aware of the biological impact of cancer.

I didn't hide anything from them because I think that it is wrong, they need to know to be aware. (Lesley: 39,27)

However, when dealing with the emotional impact of cancer, Lesley mentions choosing deliberately to hide the distress she was experiencing.

I tried to be ...um...as happy as I possibly could but I mean obviously there was dark times, especially at night [...] But we tried to make it...a positive time for the children. (Lesley:40,26)

(I) ...you were putting on...

A front [...] to, you know, to show...that it wasn't going to get me. (Lesley: 41,2-8)

Lesley's account conveys how her experience of being a mother with cancer led her to construct a public façade to reassure and protect her children, and conceal from them the emotional distress she suffered.

For those participants who were not mothers at diagnosis, there seemed to be a general sense of grief for this potentially lost identity. To minimise the recurrence of cancer, many women with breast cancer are advised to take hormone medication for five years, while avoiding getting pregnant. Louise starkly described the potentially awful paradox, in this altered, life-death relationship to motherhood.

I can't afford to get pregnant, because it could, it would kill me, coz the oestrogen... (Louise: 64,4)

Despite not seeing herself as particularly maternal before cancer, Louise now found herself to be sad at the prospect of missing out on the experience of her own child, and of the shared joy she could provide to a partner through motherhood.

I'd really like to have seen what a little me would have been like. (Louise: 16,14)

I'm never gonna do something or be pregnant where my partner is so pleased. (Louise: 16,27)

While Becky also observed that she had not felt especially maternal, she experienced sadness - and possibly anger? - at the loss of control over the possibility of being a mother.

It's one thing not wanting children, or deciding not to have them, it's another being told you can't. (Becky: 45,4)

Rachel's account emphasised how the potential loss of this highly valued identity made her question the value of her own existence.

Because of the treatment, tablets, it was like, oh well, now I'll never have kids at the early stages, that I did continue with that, well, what is even the point of me going through with all this treatment? (Rachel: 46,5)

In a long statement in her interview, Rachel describes her dilemma over taking the hormone medication, and its possible implications for motherhood. The quote here captures the root of her dilemma: that the cancer medication may prolong a life which is empty of the identity she so treasures. In this sense, in limiting Rachel's potential to be a mother, breast cancer also seems to be asking Rachel to make fundamental questions about the meaning of her life.

In summary, then, the experience of breast cancer appeared to be associated for most women with largely negative changes in the identity of mother. This needs to be set against the high value placed on this identity by many women, as indicated by their spontaneous raising of the role, and its frequency of occurrence across participants. For those who were already mothers, these changes involved a struggle to protect their children from the emotional and practical implications of breast cancer, as well as accompanying emotions of fear and guilt. For women who had not had children, there was a prevailing sense of sadness at the reduced likelihood of being a mother.

3.3.3 Employee/Work Colleague

Of the participant group, seven women were in paid employment at the time of their cancer diagnosis, while one woman worked full-time caring for her children. Their work identity appeared to raise particular challenges for participants during their experience of cancer, due to it being a point of intersection for managing issues such as embodiment, the social construction of cancer and the meaning of cancer.

The physical impact of cancer and employers' reactions to cancer were issues with which all women wrestled. Rachel worked in a healthcare setting, and perceived herself to be lucky in the support she had been offered.

My managers, they would say, just take whatever you need [...] I would be tearful and so not really coping very well at being at work [...] they got a locum in to do some of my patient work [...] and I get five months off full pay. (Rachel: 24,24-25,9)

Moreover, she did not feel that her absence during cancer treatment had affected her standing within the organisation, as she noted that "I actually just got a promotion, a couple of weeks ago" (25,16). For Nina, her experience with breast cancer meant that she deferred plans to return to work outside the home, as she felt she needed more time to deal with the effects of ongoing medical procedures.

I've still got another operation to go [...] and I [...] don't want to load it on myself yet. I think I need another year. (Nina: 46,12)

However, many women described difficult experiences as they struggled to balance their physical condition with the work environment. Gilly made a dramatic comparison between her capacity to work before and after cancer.

Before I could cope with it because I had more physical strength but now it's killing me [...] I go to bed as soon as I get home at four... (Gilly: 20,12)

In her description of work "killing me", Gilly seems to be expressing the huge toll which the demands of work are making on her life. However, I wondered

whether there was another level of meaning in the phrase, as in the final super-ordinate theme she appears to link the arrival of cancer with stress in her life; in this sense, work might be more directly involved in “killing” her. It is clear from this excerpt that work is not only having a debilitating physical impact on her, but also limiting her capacity to engage in other areas of her life – linking to ideas in the first super-ordinate theme, “Just me in a body”. In her interview, Gilly mentioned that she had not disclosed her breast cancer to work colleagues, as she was not particularly friendly with them. However, from comments elsewhere it appeared possible that this non-disclosure might relate to concerns about how her employers might react to her cancer:

They’re still paying a lot of money for you to do a job, you shouldn’t be working in their eyes, probably...(Gilly: 33,23)

As described earlier, the motivating force underlying Gilly’s work identity is her role as a mother, and her commitment to provide for her children. She seems here to be fearful that others’ perceptions of her cancer might affect her capacity to work, thereby affecting not only her work role but potentially also her role as a mother.

Difficulties managing the physical impact of cancer and employers’ reactions were also observed by other participants. Louise found she was at risk of losing her work identity altogether. Her employers did not appear to appreciate the wider personal significance of cancer, but perceived absence from work for treatment as a loss of productivity, with consequent elimination of salary.

Coz I’m only a contractor, when I was first diagnosed they weren’t going to pay anything. (Louise: 27,31)

Due to the interventions of one manager, Louise was able to be paid to work from home. However, within a treatment regime requiring surgery, chemotherapy and radiotherapy, she described feeling that “the whole cancer thing has become my life” (30,3). Her absence from work, combined with her physical state, meant that she was feeling less confident about her capabilities and status in her work role.

I just need to be refreshed on all these things [...] I just feel that I'm not in control any more [...] I'm just Louise their administrator who's had cancer and hasn't really been able to do very much for them. (Louise: 25, 18-23)

Towards the end of this extract, Louise appears to be presenting herself as she feels others might see her, with the perception that cancer has subtracted from her role competence in colleagues' eyes. Her account also raises existential questions about her experience of the boundaries of personal control, in links with the third super-ordinate theme. This is an issue which Lesley struggled with explicitly. She first recalled the difficulty she experienced, combining cancer treatment with work.

When I was going to start the radiation I went to pieces again with it all, so this is when I had to give the job up because I was exhausted a lot of the time. (Lesley: 18,11)

However, Lesley then described that, following an agreed period of work absence, she was made redundant by her manager.

I don't even believe she had any intention at that time even to take me back, it was a way of getting me out without having to pay me any redundancy or anything. (Lesley: 20,30)

The emotional intensity of Lesley's anger and sense of rejection appeared partly captured in her blunt summary that "she didn't want me and I just felt very cheated" (19,29), and I perceived a deep feeling of betrayal in the slower, deliberate phrasing of Lesley's words and her firm tone. Perhaps Lesley's sense of being cheated traced to the fact that her employer had not been open, or followed appropriate rules and processes. However, I also felt there might be another interpretation, where cancer becomes the agent which swindles her out of her job. Whatever the interpretation, in this particular work context cancer also was associated with being de-valued as an employee.

In addition to coping with challenges to their value as an employee, many women also discussed challenges relating to the social context of work. There

appeared to be two aspects to this issue. The first related to the women's own ability to manage social situations thrown up by cancer.

I were very upset all the time, I could have easily....I didn't want people to see me upset, basically. And I didn't feel very good about myself. I felt, you know, I was a really bad colour. (Zoe: 28,18)

Zoe chose not to go into her work premises during cancer treatment. Here, she talks of being worried that she would break down in front of others, and of feeling embarrassed by her looks. Louise also mentioned concerns about her imminent return to the office.

This person who they always thought was so glamorous [...] I feel like a bit of a fraudster now. (Louise: 27,8)

The contrast between her appearance before and after cancer treatment seems to leave Louise feeling a sense of shame: she sees herself as a "fraudster", pretending to be someone she is not. In their different ways, the kinds of cancer treatment Zoe and Louise received appear to have resulted in an appearance which is socially devalued, causes them shame, and leads to difficulties for them in the management of a public work identity. However, these difficulties do not trace only to their own reactions and to appearance; they also trace to the difficulties others experience dealing with participants' cancer.

It's other people's reactions really, coz I saw someone in town ...[pause: 5 secs]...she kind of avoided me, this girl...She wasn't part of the team, she works in the same branch, and maybe she didn't see me, but I think she saw me and avoided me. (Zoe: 26,11)

Here, Zoe perceived herself as someone whom others wanted to avoid. Considering the linguistic constructions in this account, I was left with the sense of oppositional forces: "I" versus "other people"; "she" versus "me". Zoe went on to suggest that it can be awkward addressing cancer issues with others, as the absence of social protocols means people "don't know what to say or how to deal with it" (28,31). Thus participants perceived cancer as

raising stigmatising social issues in the workplace, both through the presentation of their altered bodies and through the lack of accommodating discourses with which cancer can be discussed.

Set against these negatives challenges to their work identity, many participants also reported changes in their relationship to work which they viewed more constructively. Some women made similar statements to Zoe, who indicated that the priority of work in her life had altered.

I'm not going to take it seriously..[.].. it's only work. (Zoe: 27,17)

For two women, the experience of cancer had led to a significant re-evaluation of content of work, and the meaning which work assumed in their lives. Becky described how a shift in values was leading her to consider a new career.

All the petty um things that people worry about, office politics, just seem to me absolutely ridiculous [...] I spend my whole life making money for other people, most of whom are not very nice and wouldn't you know hesitate trampling all over you, um. I don't want to do that any more, er...it pays the bills, um, but I want to do something where I'm helping somebody else and that's where the counselling comes in. (Becky: 46,2-11)

In this extract, Becky seems to suggest that she no longer feels comfortable with the business and practices of her work. She indicates that her experience with cancer is encouraging her to explore work where, rather than competing with others, she is supporting others. After leaving her former job, Lesley also describes seeking an alternative career working with disabled children, and her account amplifies potential identity issues which underpin such moves:

..it's just pin money but it's more for...me feeling that I'm, I am somebody and I'm giving, helping these children that, it's giving me strength as well and helping them in the same process. (Lesley, 14,3)

Make them ...have a better form of life, you know, if I can give them some of my strength of some of my time...and make them laugh [...] then I think I'm doing my job. (Lesley: 16,26)

It appears the particular content of Lesley's new work allows her to feel valuable ("I am somebody"); in this way, the particular work she has chosen both gives her strength, and allows her to give of the new embodied sense of strength alluded to in the first super-ordinate theme. My hypothesis, then, is that such changes in career after cancer can be a means not only of expressing different, more altruistic values, but also a means to re-build an individual's personal strength after a debilitating cancer experience.

In summary, the majority of participants experienced significant changes in their work identity through cancer. In part, these related to the difficulty of managing the physical impact of cancer treatment while performing work responsibilities, and a perceived understanding or support from employers. But participants also experienced difficulty in negotiating the social environment of work, where the stigma of cancer appeared to affect both their own reactions, and those of their colleagues. More positively, cancer had in some cases led to desired changes in work identity, where participants sought careers which offered more altruistic values. For all these reasons, the work identity seemed to be experienced as a complex and challenging one.

3.3.4 Friend

All participants noted changed perceptions of their identity as a friend. Interestingly, these perceptions appeared to fall into two broad patterns, both of which included positive and negative changes. These patterns within the friendship identity did not obviously relate to marital status, and seemed to trace more to intra- and inter-personal situations.

The first pattern of identity changes revolved around a greater appreciation of friendship. Indeed, some participants believed their friendships were critical in coping with their breast cancer.

They're the people who have really got me through it and supported me. (Louise: 32,6)

Louise was not in a romantic relationship when she was diagnosed, but her single status does not appear to have been a decisive factor in this valuing of

friends. Lesley was married, but also placed immense importance on the contribution of her friends, whom she perceived as “giving me strength to carry on” (4,26). However, alongside the overall increased importance placed on friends came a greater discrimination of friendships. Several participants highlighted a smaller group of what Zoe termed “true friends” (29,25) who could be trusted to show emotional understanding as well as practical help.

They were just there to ...tell me they cared. To make me meals, take me out to eat, to listen to me when I was low and upset... and they were there when we could have a laugh together as well. (Lesley: 29: 25)

The opportunity to express difficult emotions was also noted by Zoe, who commented that “I could cry in front of her and it didn’t matter” (30,8). Perhaps this characteristic may have acquired particular importance in friendships, because of the need to restrict emotional display in other identities such as mother or work colleague, for the perceived protection of self-image or the wellbeing of others.

However, within an overall raised appreciation of friendship, such discrimination also resulted in some friends being judged as falling short. Rachel described her disappointment at the behaviour of one of her oldest friends:

I was just so upset. I told her what...and she just didn’t ring to say, how you doing, when’s the operation, you know. Nothing....(Rachel: 28,17)

Again, Rachel’s account reinforces the earlier point concerning the increased importance of emotional understanding within friendship during the experience of breast cancer. Against the heightened need for support, such failures in support acquire greater value. In Lesley’s case, she perceived the emotional abandonment by her former friend as meriting the word “abuse”.

There was one friendship that’s gone totally the other way [...] I feel she abused me [...] she just wasn’t there for me and that hurt a heck of a lot, and that friendship now has died. (Lesley: 30, 7-14)

As Lesley indicates here, for many women the discrimination in friendships resulted in the editing of their friendship groups. Ursula expressed this as a decision to “clear out a few bits of dead wood” (11,19), and went on to explain the reasons for her choice.

I think you can outgrow friends [...] I don’t want to waste time on people I don’t like any more. (Ursula: 12,5-14)

Ursula’s account suggests that the experience of cancer has made her re-evaluate the worth of her friendships, and within the context of a finite life, to make more brutal choices as to whom she spends her time with. Moreover, she also indicates that her own experience of growth through her cancer experience has given her different perspectives, which may also provide criteria for choosing some friends over others.

Set against one pattern of a greater valuation of friendships is another pattern, where there is an awareness of the lack of much-needed friends. Gilly described how breast cancer had exposed an absence of support among those people she had considered friends.

The people you thought were friends you realised weren’t friends at all [...] I wouldn’t really say any of my friends have been actually there for me. (Gilly: 26,6)

In her experience after cancer, Gilly perceives connections between her physical state and her different identities. She is upset at her lack of friends, but sees it as a result of prioritising the roles of mother and employee, within her current limited physical state.

That’s what’s so sad about my life, I don’t have time for friends [...] My life’s all about work, my children and going to bed. I’m too tired! (Gilly: 28,24-28)

Becky’s experience of cancer also highlighted to her how she “didn’t really have that many friends as such...[they were] all work acquaintances” (21,25). However, this had led her to begin seeking out new friendships, which offered

her qualities of reciprocal emotional support which she perceived had been missing before.

Somebody giving you a hug when you're down...being able to do the same for other people...(Becky: 22,11)

However the state of friendships was assessed, almost all participants commented on the challenges of communicating with friends through cancer. Sometimes the challenge could be practical, as Louise mentions here.

The winter months I was quite isolated because a number of them couldn't see me because they had infections. (Louise: 32,22)

Here, Louise's altered embodiment appears to be affecting her identity as a friend, as her compromised immunological state separates her from others. At other times, the challenge of communication appears to lie with the complex personal and social constructions with which cancer is invested. Becky described that she was cautious in disclosing her own experience to others, as "people [...] I thought were close [...] just couldn't deal with talking about it" (23,16). She explored her reaction to this in a complex image:

It's almost like [...] you've flashed at somebody...and you feel like you've exposed yourself, and you really kind of wish you hadn't. (Becky: 24,14)

The potent simile within Becky's account of having "exposed yourself" indicates the depth of social shame that may be felt when the acknowledgement of cancer is not well received. While others' reactions may be a function of social practices relating to the uneasy discussion of cancer, it also appears that participants often feel that much of this social awkwardness attaches to themselves, and by likening herself to a "flasher", Becky appears to be indicating the stigmatised status she feels in such conversational situations. Perhaps this links with the final challenge in communication, which was noted by Nina.

You can tell your friends what's happening, but there's an awful lot not happening, it's just being. (Nina: 24,28)

Whatever the value of friendships, Nina appears to perceive that it is easier to convey the factual process of cancer than the experience of having cancer. As we shall see later, this qualification of the limits of the friend identity links with the theme of autonomy, in the third super-ordinate theme.

In summary, the experience of breast cancer led all women to a greater appreciation of their identity as a friend. For some participants, this was a broadly positive experience, resulting in a greater appreciation of existing friendships. For others, the experience was more challenging, due to an awareness of the lack of the friendships they desired. Moreover, the achievement of this identity was made more difficult for all women, due to the communication challenges of building and maintaining friendships during cancer.

3.3.5 Survivor

The identity of a cancer survivor is different from other identities mentioned here, in that it is self-evidently only made available through participants' experience with breast cancer. It is notable that, while frequently mentioned in patient support literature on cancer, the identity was only raised spontaneously by two participants. However, in subsequent interviewer questioning, it was clear that many participants were aware of the identity and had reflected on it. This hesitancy in mentioning the identity may trace to its newer status, but it is also possible that it derives from the polarising reactions it provoked. While a few participants actively embraced the survivor identity, there were an equal number who violently rejected it. These differing reactions appeared to stem from varying definitions of the identity's content, and the value participants attributed to this content.

Even amongst those who viewed the identity positively, there were differing conceptions of the identity's content and their allegiance to the identity. Ursula defined the identity literally, as "somebody who has had cancer [...] but has not

died" (37,4). Her willingness to embrace the identity seemed linked to the positive prognosis she had received when diagnosed.

I've felt a survivor right from the start. They were that confident with me. (Ursula: 37,12)

Ursula's interpretation of the survivor identity supports another identity described later in the third super-ordinate theme, which relates to autonomy, and thus the identity can be accepted. Nina also appears to accept the survivor identity, although with a different definition.

...there is always an amazing feeling of having survived it. You know, it is emotionally and physically a big thing to go through, and you have done it. (Nina: 51,7)

Here, the identity of survivor is described as a euphoric feeling, derived from emotional and physical accomplishment. While Nina's use of "you" rather than "I" suggests she may be slightly bashful about claiming the achievement, she perceives that being a survivor denotes the effort and wonderment of successfully completing cancer treatment. For Lesley, there is more uncertainty in claiming the survivor identity. She reflects that "I feel like I'm a survivor", but then goes on to assess the grounds on which she perceives the identity to be based.

I am on the Tamoxifen for five years, which is supposed to keep it at bay, if anything, any nasties reoccur, but whether I'll be totally mentally free from cancer, I don't know. (Lesley:51,5)

Lesley's account suggests that she equates being a survivor with being both physically and mentally free from cancer. While she can tentatively believe her ongoing medication will avoid the physical recurrence of cancer, she appears to be less confident of leaving behind the psychological experience of cancer.

Other participants are reluctant to claim the survivor identity, believing that they don't fulfil its requirements. Louise perceives that she will only be eligible to be a survivor "in five years' time when I've had the all-clear" (59,8). She

uses the military imagery she employed elsewhere to describe her embodied engagement with cancer, suggesting that she has “survived the battle but I’m still on the journey” (59,19). In this way, she appears to define the identity by robust physical prognosis. For Gilly, being a survivor seems to be associated more strongly with her psychological state. She is clear that “I don’t feel I’ve survived it. I’m not a survivor at the moment” (79,20). While she does not appear to reject outright the possibility of being a survivor at some stage, she asserts that “I don’t think I’ve even got anywhere near the realisation, because you know everything’s such a whirl” (79,29). As with Ursula, the willingness to consider the survivor identity seems to connect with other identities; Gilly’s description of herself as “lost” within the third theme of the final super-ordinate theme seems to link with her struggle to see herself as a survivor at this stage.

Finally, some participants reject the survivor identity outright. Many women voiced the difficulty of capturing their relationship with cancer, and Becky’s struggle is echoed by other participants such as Lesley.

I find it quite difficult [...] to know what to say. (Becky: 50,3)

I never know [...] how to describe myself. (Lesley: 51,2)

However, Becky’s experience with cancer has led her to reject any cancer-specific identities, in favour of simple description.

I wouldn’t use any of them [...] too emotive words. (Becky: 51,27)

I’ve said I had cancer last year. (Becky: 52,1).

Becky appears to suggest that, for her, the identity of survivor is too laden with feelings and connotations which she is not willing to embrace. While she does not elaborate on this directly in her account, it is possible her unwillingness relates to the intermittent depression and fear of cancer’s return, which she alludes to within the later theme “Assessing Autonomy”.

Rachel is clear and categorical that she “didn’t want to be seen as a cancer survivor” (52,1). Initially, she suggests that this is because she wants to move on from the experience of cancer, rather than have a label which is a continuing reminder.

If you’re a cancer survivor, it’s almost like you’re proud that you’ve had cancer. And it’s not that I’m ashamed that I’ve had cancer, it’s about wanting it to be done. (Rachel: 62,29)

However, this extract also raises something of the complicated, “emotive” connotations that the survivor identity can assume. Rather than being proud of the achievement of surviving cancer, Rachel seems to suggest that being a survivor could be seen as being proud of having cancer itself. While she immediately states here that she is not ashamed of having cancer, a subsequent comment hints at a social awareness of taking up an identity attached to a potentially stigmatising subject.

I don’t want to tell everyone that I’ve had cancer [...] and that I’ve survived cancer. (Rachel: 63,11)

For Rachel, and perhaps Becky, a continuing association with cancer as a survivor appears to be seen as allying one’s identity with something which is socially awkward and devalued, and thus the identity is rejected.

In summary, the new identity of cancer survivor was one which all participants had considered, but which all almost found to some degree problematic. In part, this traced to lack of clarity regarding the content of the identity. Participants reflected on the varying ways in which physical survival could be defined, as well as considering the issue of emotional survivorship or psychological wellbeing after cancer. Moreover, the uneasy social status of cancer meant that while surviving cancer could be seen as a significant achievement, being a cancer survivor could also be viewed as a potentially stigmatising identity. As a result of these different definitions, some women appeared to consider expanding their identities to include the new role, while others explicitly rejected it.

The second super-ordinate theme has considered how, in the wake of their cancer experience, women re-evaluated previous role identities and considered a new identity. While some change was valued, much change was experienced as difficult, largely due to social constructions which stigmatise cancer and position the display of distress as a weakness. The connection between embodiment and role identities has been evident in each role. However, there are also vital links to emotional-existential identities, which will be outlined in the next section.

3.4 Emotional-existential dilemmas: Re-learning what life's all about

One definition of identity regards it as "the condition of being a specified person" (CED, 1984). This final super-ordinate theme addresses issues relating to the fundamental nature of being human, and how these issues are played out in an individual's life. The experience with breast cancer appeared to ask these women to consider the limits of their embodied personhood, and this is represented in the first theme, "Facing my own mortality". The second theme deals with participants' perceptions of their own capabilities, and is entitled "Assessing autonomy: Strength and vulnerability". The final theme, "Following a different path to before", explores the extent to which participants experience breast cancer as having led them in a different direction with their lives.

The overall title of this super-ordinate theme needs further elaboration. In responding to the question "Who Am I", participants responded spontaneously with these emotional-existential responses, which seemed to be given the same weight and status in identity terms as other responses (e.g. role identities). Thus, this theme should not be seen in any way as inferior to other super-ordinate themes. Indeed, as I shall suggest at the close of this chapter, this might be seen as the most significant of all themes, in terms of overarching identity concerns. Moreover, the choice of the word "dilemma" was deliberate; although a somewhat hackneyed term, it does capture the unresolved and unsettling quality of many of these identity issues.

3.4.1 Facing my own mortality

Participants in this study had been diagnosed with earlier rather than advanced cancer stagings. However, for all women this diagnosis appeared to have resulted in consideration of their own mortality. This consideration took several forms: assessment of the nature of life; understanding their own personal relationship with death; and taking a position on socially-raised issues which might be associated with their mortality. Participants' quotes were notable for the variety and vividness of the imagery they employed, suggesting the emotional depth – and mythic nature? – of the identity issues raised.

Many participants commented on the way breast cancer brutally confronted them with a sense of the fragility of their lives. Becky seems to convey feelings of shock, horror and disbelief on receiving the diagnosis:

How can you be okay one minute and then in the middle of a nightmare the next?
(Becky: 34,2)

In her account, Becky describes the speed with which her perception of life changes. By employing the image of a nightmare, she seems to imply that the cancer feels almost unreal: a bad dream, where definitions of reality are distorted and frightening. Zoe's account also emphasises the speed and impact of being diagnosed with cancer, but here the image is one of being violently assaulted:

And then you get hit, you find that out, and everything changes. You can never go back to being like that, never. (Zoe: 6,33-7,2)

Zoe seems to be suggesting that her sense of life and living has been fundamentally and comprehensively ("everything") changed by her contact with cancer. Her reiteration of the word "never" perhaps conveys her sense of the impossibility of un-knowing this knowledge: that cancer has brought about irrevocable change in the nature of her existence. Louise finds the sense of fragility captured not just through before-after temporal differences, but also through real-time comparisons with another.

And she [Jade Goody] was the flipside of the coin. This is like me fighting it to survive, but this is what can happen. And I remember the day she died, I can remember just thinking, where's she gone? Where's she gone now? Coz in my mind it was so close to what could happen to me... (Louise: 38, 4-9)

Louise's image of the flipped coin evokes the idea of an impersonal fate, in which mortality is decided in the lucky toss of a coin. In taking up media coverage of Jade Goody's death, Louise explores a cancer experience which parallels her own in time, but which leads to a different outcome. The rhetorical questions in her account indicate her own struggle to comprehend the mystery of death, and how an embodied being like herself can disappear.

Louise's comments link to a second aspect of this theme. The experience of cancer required participants to consider their own personal relationship to death. For many women, this was a dark and difficult area, and their descriptions hint at the emotions of fear and sadness underlying their experience. Becky appears to describe a sense of lost innocence and confidence, where she no longer perceives that she has the power she thought she possessed.

It made me face my own mortality [...] before that you just go on like a child, thinking you're invincible. (Becky: 8,21)

Becky's two images suggest different aspects of her experience. In her phrase "face my own mortality", the physical sense of "facing" someone may allude to a different placement towards death; almost a feeling of squaring up to death, both physically and psychologically. Becky contrasts this new stance with her perception of herself pre-cancer, and the image of a child appears to mark her sense of having aged in her attitudes and identity. Other participants echoed similar experiences. Gilly described feeling frightened at "the thought of death closer to me" (60,17), and this image appears to evoke the sense of death as a presence which is now in much greater proximity to her. Like Louise, Gilly made use of media accounts to provide perspective on her own experience.

I thought sixty was young to die [...] but then look at Natasha Richardson, you know, she dies of skiing. (Gilly: 61,7)

Gilly seems to suggest that her own experience of death seeming closer is not excessively pessimistic, given the death of the actress in her forties. Whilst she previously appeared to consider death as something which occurred at an older age, the possibility of death at a much younger age now seems much more present to her. This is something which Zoe also addresses directly.

The only thing that we're sure of in our life, that one day we're going to die. I suppose I were being a bit premature then, but...you don't want to die when you're forty or thirty-nine, do you? You want to see your kids grow up [...] You're faced with that...and I'm not ready for it, I just want...so I think I've aged in that way. (Zoe: 9,3-9)

Linking with her earlier description of experiencing her body as much older, Zoe considers here how she feels herself to have aged psychologically, through contemplating existential issues such as death before the normal time. Zoe seems to capture here much of the dilemma for many of the younger woman participants, where active involvement in mid-life identities such as being a mother or work colleague is abruptly juxtaposed with the possibility of the end of life. The difficulty many participants found in recognising this new, mortal self appears to be captured in the switch between "I" and "you"; for example, in her extract here, Zoe could be interpreted as using the you-form to embody the alternative death scenario ("you don't want to die"), with the "I" being used for her own present situation ("I'm not ready for it").

While many participants were fearful of the possibilities of more imminent death, some women described a more benign stance towards their mortality. Ursula viewed herself as "lucky" (1,8).

This potentially dreadful thing's happened, but [...] it's happened in a way that's not going to kill me. (Ursula: 3,2)

Here, Ursula's description of the "potentially dreadful thing" appears to resonate with scary monster evoked in the first theme, and indeed the "thing" seems to have the agency to "kill" her. However, Ursula's diagnosis of early

stage breast cancer, and her confidence in her doctors' opinions, meant that she perceived cancer as not being connected with death for her personally.

Had the utmost confidence in the doctors when they said it's not going to kill you [...] never [...] at that point where I'd think, oh God, I've got cancer [...] therefore I'd better make a complete lifestyle change. (Ursula: 18,26)

Ursula's experience of mortality appears to differ from previous accounts, in that while she conceives of it as a possibility, she does not describe experiencing it in such present and personal terms. This difference in sense of mortality, and sense of clarity of prognosis, seems to link to Ursula's readiness to take up the identity of a cancer survivor, as mentioned in the second super-ordinate theme. However, another participant seemed to draw reassurance not from a distancing from mortality, but from engagement with death. Within the super-ordinate theme of Embodiment, I presented Lesley's account of the new strength she perceived in her body after cancer; here, Lesley appears to connect this new embodied identity with an altered approach to mortality.

My body obviously fights these things...you know, me mother says I'm a cat with nine lives... (Lesley: 5,26)

By employing the image of the "cat with nine lives", Lesley suggests that she is a creature for whom death will come, but that it has not been her time so far. In the symbolism of the lucky cat, Lesley perhaps alludes to some element of good fortune in her situation, but she also reflects on the power of her own body to resist death.

Finally, in facing their mortality, many participants appeared to be confronted with social commentaries concerning life practices and cancer. Rachel talked of the difficulty she experienced reconciling her previously healthy lifestyle with the cancer diagnosis.

People have said to me, you're the healthiest person I know [...] so that's just made me think, is that just a load of rubbish? (Rachel: 21,20)

Within a general society which promotes eating patterns and exercise to prevent cancer, Rachel seems to emphasise her scepticism through the use of extremes (“healthiest”-“rubbish”). Nina also questioned the value of information supplied after diagnosis, concerning environmental factors which were potentially linked to cancer.

They [...] talked about a lot of things you can change: your diet [...] whether you use perfume. I don't want all that information. I don't want to feel that I've got to change everything, because nobody knows what it is. (Nina: 43,7)

In her repeated use of the phrase “I don't want”, Nina appears to convey frustration with socially-recommended practices which she perceives might have a significant impact on her life, but cannot be shown to have an impact on mortality. There is perhaps also a sense of anger with the way cancer becomes an individual responsibility, which parallels the way in which cancer can be represented socially through the stigmatising of individuals: in its extreme, cancer becomes a personal “choice” or judgement. However, Ursula viewed these same practices differently, and made the decision to change her diet and take up more exercise.

Why trust everything to luck, if there's something that I can do that might make a difference. (Ursula: 5,9)

In what might be seen as a qualification of her previously articulated sense of good fortune, Ursula seemed to believe such practices worth trying in case they do positively impact her mortality.

In summary, the experience of breast cancer appears to have asked participants to assess where they stood, in relation to death. This identity is related to, but not the same as, the issues of embodiment described in the first super-ordinate theme. Here, the embodied nature of the women is the starting point for existential questions concerning mortality, and their associated emotions. Participants commented on significant changes in this area of identity: their new sense of the fragility of their human existence, and how – for the majority of women – they experienced a different proximity to death

after cancer. Social practices such as diet and exercise were assessed for utility and value in coping with their mortality.

3.4.2 Assessing autonomy: Strength and vulnerability

As a result of breast cancer, almost all participants appeared to experience altered perceptions of their own capabilities. For some participants – or for some qualities within an individual participant – this change was minor, and involved only reaffirmation of previously held perceptions. At other times, the experience of cancer added a significant new awareness of capabilities. These changes fall into two broad areas: those where capability was perceived to have been enhanced, to which I have given the overall title of “Strength”; and those where capability is perceived to have been diminished, entitled “Vulnerability”. It is worth noting that perceptions of both strength and vulnerability were often experienced within the same participant.

3.4.2.1 Strength

Some participants suggested that their experience of cancer had reinforced their sense of personal capability. Ursula viewed herself as a “tough old bird” (42,26), who had always looked after herself and got on with life. Coming through breast cancer seemed to have affirmed this identity, representing a personal achievement against a formidable challenge which endowed her with particular status.

In a morbid kind of way, a bit special, because [...] I’m one of a small group of people that have had breast cancer and survived. (Ursula: 48,33)

For Gilly, breast cancer had provided further evidence of her ability to survive despite very difficult circumstances.

Against all the odds, losing lots of money through relationships [...] no support, I’ve brought up two beautiful children and kept my head above water. (Gilly, 34,11-16)

In links with her identities as mother and employee, Gilly appears to see herself as “successful” (34,9) due to her ability to support her children and to keep going, in the face of what she perceives as particularly demanding events (“against the odds”).

However, for some women these perceptions of strength were more problematic. Rachel asserted that “I feel that I’ve coped with it [breast cancer] very well” (50,18), but then acknowledged issues she had perceived to be associated with such coping.

It’s this terrible thing, it’s kind of like a sense that I’ve...I’m strong because I ...don’t really need any help...and it’s in such a contrast of this feeling of being alone and wanting to be around people...(Rachel: 50,28)

Rachel seems to be raising questions about the appropriateness – and value? – of this sense of being strong, in that this identity appears not to enable her to voice her loneliness or need for support: a distressing paradox she names “this terrible thing”. In equating the social performance of being strong with the not asking for help, Rachel appears to be inferring social rules required for valued public behaviour; this echoes Zoe’s experience in her work identity, where she described how she was concerned about displaying her distress within the office environment. Louise describes similar issues with the quality of bravery, and suggests that such issues may arise from a social context which values particular behaviours.

They say, ...you’ve gone through, you’re on your own, you’re so brave. (Louise: 43,29)

I am brave as in I don’t let the side down, telling them all (Louise: 44,2)

They don’t realise that when they left I probably would be in floods of tears, because I was putting on. (Louise: 45,4)

In these extracts, Louise highlights the difference between friends’ definition of her bravery, and her own understanding of this term. Within the wider social context, she perceives others to define her bravery by her ability to cope without the support of a close partner. However, Louise’s personal definition of

bravery appears to involve keeping the difficult experiences of cancer away from her friends. She seems to allude to a sense of informal codes of performance which require such behaviour ("I don't let the side down"), resulting in a discrepancy between her public display and privately-held emotions ("I was just putting on"). Indeed, Louise later questions the true substance of this strength, suggesting that – on external requirements for bravery - another way of viewing this quality might be to judge her a creditable performer.

I'm brave as in, either that or a good actress. (Louise: 45,19)

Louise's comments appear to link this identity with that of being a friend, which – as described earlier - she highly values. However, these statements also reinforce previously mentioned issues concerning communication within friendships, as well as highlighting the way social context can constrain the realisation of individual identities.

An important change for some participants was greater self-respect. Rachel described how, through the requirement to cope with an experience as significant as cancer, she had felt more able to assert her own needs.

I'm a bit less prepared to put up with the, where you know in the past I would never have said anything [...] It's been like every one of my friends has had a big thing going on [...] there's been part of me which has thought, yeah, but I've got cancer. (Rachel: 56,18-30)

Rachel's account suggests that she perceives the experience of coping with cancer to be a greater challenge than those experienced by her friends. This has made her less willing to accept inadequate support from others. Becky describes a similar change, but attributes this difference not to comparison with others but – in a link to the previous subordinate theme - with her heightened awareness of mortality.

More able to say that now [...] if they don't like it, tough [...] Life's too short to waste time being with negative people [...] not people who are down or upset or frightened... [...] generally, right miseries, you know. (Becky: 12,8-18)

Here, Becky describes how breast cancer has given her a sense of life's brevity, and this has given her greater confidence to choose to be with certain kinds of people. Moreover, this choice might be seen as a virtuous circle which reinforces her sense of strength, as Becky mentions that she aims to "be with nice people who are positive [...] making me feel positive...everything is geared towards being kind to myself" (13,3).

3.4.2.2 Vulnerability

While participants often described their capabilities as being reaffirmed or strengthened through the experience of cancer, there was also frequent mention of the ways in which cancer was perceived to have negatively affected their ability to cope. Louise describes her general sense of loss, and her feelings of being unfairly treated by life.

I kind of felt cheated that I'd literally found happiness and then I got this. I felt cheated that I was too young to have this and I felt cheated that it's, it stole my body, and um. And I felt cheated as well that I um didn't have a family that was there, too...(Louise: 42,26-31)

The iteration of the phrase "I felt cheated" seems to convey the extent of Louise's anger: that cancer has arrived at an unusually young age, and has both taken away things she prized (her body; her happiness) and exposed her lack of family support. Moreover, in the phrase "it stole", Louise seems to experience cancer as a malign thief, who has swindled her out of things which were rightfully hers. While Louise has elsewhere suggested her sense of being brave, she indicates here that her sense of autonomy has been compromised by life events, and this has been particularly highlighted through her experience with cancer. Rachel also described how having a mastectomy had left her with a different sense of unhappiness from before cancer.

It's different from how I'm ordinarily unhappy because there's an actual reason, rather than just get quite low [...] it was something that I couldn't control. (Rachel: 35,14-18)

Rachel's comments suggest that while this qualitatively different unhappiness traces partly to being grounded specifically in cancer, it also links to her sense of loss of autonomy: she has had no choice about having cancer. In both participants' accounts, then, cancer appears to be presented as something definite and solid, a force to be reckoned with.

All women described feeling vulnerable, in their fear that the breast cancer might return. Becky mentioned how this new anxiety had disrupted previous activities such as reading or focussing at work, and the dimension of the fear she feels is accentuated by her choice of the adjective "dreadful".

Really hard for me to sit and think about [...] I have a dreadful fear [...] that if it comes back it's not gonna be quite so simple as it was the first time. (Becky: 43,26)

As alluded to earlier, it is possible that this sense of vulnerability is what makes the survivor identity so difficult for many women, for whom the sense of fear is particularly present. Zoe touched upon another aspect of this vulnerability: the discrepancy between her outwardly cheerful behaviour and her inwardly fearful thoughts.

I try and be positive...and I say positive things, but I know in my heart of hearts that I'm just being realistic, and thinking, well, it could happen, because it's happened already [...] I put that act on, but when it's just night time, or when I'm on me own...I can't hide from that, it's there in me mind...(Zoe: 14,5-31)

Zoe suggests that she makes an effort, both for herself and for others, to believe that she will not have breast cancer again; she equates this with being "positive". However, while performing "that act" may reassure others, she seems to say that private experience of fear of recurrence is not something from which she can escape. Moreover, whilst the use of the phrase "I can't hide" has resonance with the inescapable nature of our mortality in the previous theme, it also connects with the mythic, monster-like quality of cancer alluded to within the first super-ordinate theme.

In summary, the experience of breast cancer appeared both to enhance and diminish participants' sense of their capabilities, in differing but often interconnected ways. Coping with the physical and emotional demands of cancer led many participants to perceive in themselves a new or reaffirmed strength; however, this experience also appeared to have thrown up areas of vulnerability, where fear and unhappiness seemed ultimately to trace to lack of autonomy or control.

3.4.3 Following a different path to before

All participants described how the experience of cancer led them to review where they found meaning in their lives. This aspect of identity appeared to have a wide significance, affecting the range of a person's other identities, yet operating at a level above them. For some women, cancer seemed to have wholly or partly overturned previous meanings in a destructive way; others were excited by new meanings found through the experience with cancer, while yet others described a more modest adjustment to meaning.

Gilly observed that her experience of breast cancer had left her feeling totally "lost" (53,5).

I am a mother, I am a very hard-working person, I am a teacher, I'm all those things, but I don't know who I am any more. (Gilly: 5,22)

Gilly's comment indicates that she perceives her self – the "I" – to be in some ways distinct from the occupant of the roles of mother or teacher. This experience of being suggests that role identities are a necessary but not sufficient part of our total identity as a person; that there is something else which adds coherence and meaning to these individual identities, which may be hazarded as a set of personal characteristics, values or beliefs. In her interview, Gilly repeatedly stated that her experience with cancer had totally overturned her sense of these linking or over-arching values, leaving her without bearings in an utterly disordered world.

I just don't know who I am any more [...] my whole world is upside down. (Gilly: 2,6-10).

Many women noted how life had taken on a bittersweet quality, which affected both their role identities and this overarching sense of self. Louise captured the change in her overall self in describing how "I'll be going back to the life I had, but I won't be the same person" (Louise: 30,32). Here, I understood Louise to suggest that while she would be occupying similar roles to her life before cancer, she would be holding different values and sensibilities to those roles: while the roles remained the same, the content had changed. She was categorical in rejecting the frequently-raised idea of cancer as a gift which enhanced life; however, she felt that cancer had helped her better appreciate everyday things, because they meant she was alive.

They're actually glad they went through it, and I was, my God, what was your life like before? (Louise: 20,8)

I'll always appreciate it because I'll know what the flipside is [...] however bad life, whatever throws at me in life, I'll always think, it's nothing compared to what I went through. So I'll always appreciate life, so when I open that wardrobe door and everything in that wardrobe fits me, I gonna so appreciate it. I'm gonna appreciate getting into bed and getting out of it in the morning and washing my hair and blow-drying it. (Louise: 53,31-54,7).

For Louise, the change in meaning appears to trace to a different significance which future activities will take after cancer. She perceives that new problems will seem of lesser scale when compared with her struggle with cancer, while previously mundane activities such as blow-drying hair acquire greater value, as they are a sign of living an apparently cancer-free life. In this sense, Louise's meaning seems to be drawn from imagining comparisons with her previous experience. Zoe's sense of new meaning is also derived from comparisons to her cancer experience.

People have said to me, like my sister said to me, you know it makes you, it changes you coz it makes you appreciate every day and live for today [...] and that's fine, it's

thinking all that, but...the reason why I'm thinking all that is because it might not be, you know. The dread of ...it all coming back...(Zoe: 21,26)

Zoe describes how she is enjoying spending more time with her children, but in the extract above she suggests that appreciation of such daily activities arises not from joyful comparison with the past which Louise experienced, but from fearful comparison with a possible future. Moreover, in an echo of Louise's comments above, Zoe appears to struggle with social discourses which position cancer as a gift, as she finds cancer not only intensifies but also limits her appreciation of life.

Other participants described how cancer led them to reposition their overall sense of self. Rachel explicitly acknowledged this process of re-evaluation.

People say you know they evaluate their life [...] whereas actually I feel I don't have a lot of things left that I wanted to do and haven't done [...] The only thing that I would feel I have missed out on [...] I would like to be in a relationship coz I really would like to have kids. (Rachel: 43,13-26)

Here, Rachel appears to be deriving meaning from her life from an assessment of her accomplishments. Rather than perceiving significant change in her sense of self, Rachel describes how cancer has reinforced the importance she attaches to the particular role identities of partner and mother. However, Nina is clear that her overall sense of self has changed through her experience with cancer.

It's just having a new identity, having a new um feeling of being normal, but it's just a different normal from how it was before. (Nina: 33,13)

Like Gilly and Louise, Nina appears to perceive some over-arching sense of self, which is different from that which she had experienced before cancer. Her comments suggest that re-establishment of this new equilibrium is one of the difficulties following a disease such as cancer, when so much change is required in the multiple identities a person holds. Nina mentions that, in creating this new normal, she has chosen to take up new roles which amplify

her previous identities; however, she observes that she feels she has lost something of her earlier power and potential.

I have made an effort to do more things for myself than before. I've joined an art group [...] what I did before was I had friends, went out and was a mum...(Nina: 34,15)

I do feel ...a bit of a shadow of my former self. It's slightly ...a lost dreams kind of thing [...] I just don't think I would be as ambitious with myself and what I want to do next as I probably would have been before. (Nina: 29,21)

In this first extract, Nina suggests that cancer has led her to develop identities which are more expressive of her personal talents, such as membership of an art group. Thus it seems that, in this respect, her experience has encouraged her to effect greater realisation of her individual capabilities. By contrast, Nina's description of feeling a "shadow of my former self" indicates that she has a sense of an overarching self which has been weakened by cancer: indeed, she reflects that "I don't think we can cope some of the time" (29,3). Thus in links to the subordinate theme of autonomy, Nina's perception of her greater vulnerability has led her to redefine her global sense of self, and to reduce her ambitions accordingly; this space between previous and present self-identity has left her with a gap which she captures in the phrase "lost dreams".

Finally, there were participants who appeared to find enabling and inspiring meaning through their cancer experience. Becky described how she was "pulled up short and put on a different path to the one I was going down blindfolded (18,5), indicating both the sudden and fundamental nature of the change and her sense of an alternative path enhanced by new vision. Having discussed a significant shift in focus from career to building friendships through wider interests such as music and theatre, Becky elaborates further on this change:

...this whole experience of realising life's short [...] I realise now exactly what is important and people are important and I didn't really think that before...(Becky: 4,8-12)

...it's good to talk to people, it's good to share experiences, it's good to find out new things, um it's good to have friends and people who like you and that makes you feel good. (Becky: 4,24-7)

From her emphases in these extracts, Becky indicates that cancer has raised the existential issues of mortality and isolation, and she now places much greater value on the support of others. However, she also seems to convey something at the phenomenological level: a new discovery of the pleasure of relating to others, and the feeling of being appreciated by others and engaged with others ("it's good to share experiences...that makes you feel good"). This sense of being alive to possibilities appears to be a key change from her earlier, more critical approach.

Instead of beating myself and other people up, I now embrace [...] life...and that's the key difference. (Becky: 52,17)

The desire to embrace life was something which Lesley also recognised in her account. The enhanced awareness of her mortality enabled her to develop a more concrete understanding of what she valued, and the frequent use of terminology such as "I want" and "I managed" in the following extract perhaps indicates her greater determination and passion to achieve these things.

I want to be able to say, I've done everything I wanted to do with this life, and I managed to do it, whether it's seeing the world, whether it's helping more unfortunate people than myself, I want to be saying, I've lived my life to the full. (Lesley: 16-20)

But there was also a further level of meaning which Lesley perceived in her experience with cancer, and which she described in connection with her choice to pursue new employment working with disabled children.

I believe there is a reason why I'm still here. And I believe....I'm still here becausethere's something I still have to do, and in my opinion it is to help other people as much as I can, whether they're disabled or a friend in need. I just feel that because I've come through....and I have got this strength, that I have to be there now for others. (Lesley: 10,1-7).

Lesley appears to connect her cancer prognosis to a belief that there is an ongoing fundamental purpose to her life in this world. Although this is not explicitly mentioned in her interview, her account suggests a sense of a mission consistent with a religious approach to existence. Rather than being alienated from existence through an awareness of her mortality, Lesley seems to have found that cancer has given her a stronger connection to life, through awareness of a deeper purpose.

In summary, all participants reported that their experience of breast cancer caused them to assess the meaning of their lives. All participants described change, although the scale of this change varied considerably across the women according to their personal circumstances. Moreover, while issues such as accommodation to mortality, sense of autonomy and ability to fulfil role identities were implicated in this change, the importance and value attached to each issue varied by participant, resulting in individual conclusions as to the negative or positive nature of the change.

This final super-ordinate theme has considered wide-ranging identities which relate to the condition of being human. These emotional-existential identities involved the women taking positions regarding their mortality, their capabilities and the personal meaning of their lives. As with the second theme, there are many examples of life-enhancing change; however, the majority of changes seem to have been experienced as difficult and un-desired.

3.5 Drawing together the super-ordinate themes

Before relating participants' experience to theoretical literature in the final chapter, I felt that this analysis would not be complete without consideration of wider relationships between the various super-ordinate and subordinate themes, which emerged from my interpretation of these women's accounts. These comments consist of five points, although each point also has implications for the others.

Firstly, although there was a high level of commonality in the kinds of identities being reviewed, the degree and nature of change differed within the participant group. The majority of participants reported a large degree of change across the range of their identities. However, there were two women – Ursula and Rachel – whose descriptions suggested that the degree of change experienced within many identities was less significant than for others. Looking at the overall nature of change, there were some changes in embodiment or emotional-existential identities which participants viewed positively. Yet, considered as a whole, it appeared that the majority of the transitions were difficult and painful ones.

Secondly, it appears from these accounts that participants' overall sense of identity, as well as their potential for role identities, is fundamentally grounded in the body. "Challenges to embodiment" highlights how identity is linked to the appearance, sensing and functioning of the women's bodies; indeed, one of the major issues of a disease such as cancer may be the difficulties it poses for these foundations of our identities, which are less provocatively confronted in the routine of an ostensibly healthy life. I have therefore chosen to present the super-ordinate theme of Embodiment at the beginning of the Analysis, as the change and continuity in identities arises initially out of this embodied state.

The third point relates to the environment surrounding this body. Although this research focussed on the idiographic analysis of an individual psychological phenomenon, I have been very aware of evidence of how the social context has shaped these women's experience. All participants and all themes show conscious and subconscious use of social material, through social practices or employment of social discourses. This analysis has aimed to draw out some of these issues. For example, one major issue running throughout this chapter has been the ongoing stigmatisation of cancer, and the way this influences fulfilment of certain identities for younger women. Another example is the way in which emotions such as distress can be negatively associated with desired social attributes such as strength. By showing sadness or grief, participants appear to worry that they will be additionally devalued in social contexts. Both these issues may be seen to be linked within an over-arching discourse of bodily self-control.

Fourthly, I feel it is important to make some comment about the third super-ordinate theme. At the end of the research interviews, I asked each participant to rank those two or three identities which they felt were most salient or significant for them at that time. These choices are highlighted in Appendix 13. While a quantitative measure of salience is neither scientifically warranted nor appropriate to the method of this study, I felt it was an important aspect of individuals' experience that at least one of the salient identities for each woman came from within the final super-ordinate theme; moreover, this theme had substantially more salient identities than the other two themes. These choices suggest that the emotional-existential issues highlighted in this theme are at the core of women's lived experience of breast cancer, and raise important questions for the nature of identity and therapy.

The final point relates to the structure of this analysis, and indeed the phenomenon of changing identities after breast cancer. Although I believe – after much thought – that the chosen conceptual groupings represent a legitimate, coherent and rigorous construction of the accounts presented to me, I was also aware of the intricate web of connections between subordinate and super-ordinate themes. An obvious example is the subordinate theme of "Facing my own mortality". While I believed its existential content led the theme to fit best within the third super-ordinate theme, there were also clear connections to the first super-ordinate theme of "Challenges to embodiment". There are other, more detailed linkages, and I have aimed to illustrate a few of these within the Analysis. However, I am aware that it is not possible to do justice to the complexity of this web, nor perhaps to the dialectical relationships between the various identities.

4 Discussion

You cannot take a life out of history [...] life-history and history, psychology and politics, are deeply intertwined. (Gilligan, 1982: xi)

4.1 Overview

In this Discussion, I shall propose that the nature of change and continuity in identities after cancer can helpfully be understood as “biographical disruption” (Bury, 1982). As Smith, Flowers and Larkin (2009: 113) describe, it is “in the nature of IPA that the interviews and analysis will have taken you into new and unanticipated territory.” In making sense of the shape and scale of this territory, I found myself looking for ‘maps’ of identity which could help explain the new landscape. I shall argue that the broad change in embodied, role and emotional-existential identities is usefully accounted for by the framework of biographical disruption. While concepts such as “identity projects” (Harre, 1983) are restricted to a particular area of activity, the wider range of biographical disruption provides a better fit with the phenomenon experienced by my participants.

Furthermore, as the notion of biographical disruption was developed within the discipline of sociology, it is more explicitly oriented to issues of context and discourse. As a researcher, one of the unexpected aspects of the analysis was the extent to which discourses of bodily self-control and stigma occurred throughout participants’ accounts of identities. In their assessment of meaning-making and cancer, Collie and Long (2005) propose that dominant discourses can greatly constrain the meanings available to individuals, and advocate that research raises awareness of the way in which forms of speaking can impact experience. Mindful of the research criteria which Yardley (2000) outlined, I felt that proper sensitivity to context required greater attention to these questions of discourse. The framework of biographical disruption enhanced such an enquiry, as it enabled me to unpack participants’ use of

discursive material regarding the control of the body, and to do so more productively than within a cognitively-focussed concept, such as that of “threatened identities” (Breakwell, 1986).

This chapter begins by explaining the concept of biographical disruption, and describing how it illuminates the overall findings of this study. Theory relating to discourses of control and the body is then introduced and related to general issues of biographical disruption. This leads to more detailed consideration of the ways in which disruption in embodied, role and emotional-existential identities is intertwined with particular manifestations of discourse concerning body control. Finally, I draw some general conclusions about this particular phenomenon of biographical disruption. The chapter then moves to an evaluation of the study and its implications for counselling psychology, before concluding with a final elaboration of reflexive issues.

4.2 Continuity and change as biographical disruption

4.2.1 The relevance of biographical disruption

As Charmaz (1983; 1995) and Frank (1991) have argued, a diagnosis of cancer does not only affect a person’s physical being, but also their sense of self and their connections to their wider world. In developing the concept of biographical disruption, Bury (1982) sought to describe and explain these wide-scale and inter-linking changes which chronic illness can bring about. Such changes, Bury proposed, could be seen as centring in three main areas: disruptions in taken for granted assumptions about the body; disruptions in explanatory frameworks, such as questions of causality of disease and life meaning; and disruption of material and social resources available for the creation of the self. Wilson (2007) described how this biographical disruption can be manifested either through the development of new identities or through the re-formulation of previously-held identities.

The concept of biographical disruption is therefore of direct relevance to this research, in several ways. Firstly, the direct correspondence between the kinds

of change in identities reported in this study and those theorised in biographical disruption helps illuminate the nature of change which breast cancer can bring about. Change in identities following breast cancer is not restricted to a single role, not even to a particular aspect of identity, such as embodiment. Instead, a person experiences disruption across the arc of their life. As such, the notion of biography is helpful in two ways. Firstly, as Riessman (2003) describes, it suggests how the universal characteristics such as mortality and the physical body are inextricably bound up with cultural location and individual meaning-making. Indeed, though I believe the individual super-ordinate themes are a useful and meaningful explanatory device in this study, they also conceal the profound relationships between embodied, role and emotional-existential aspects of an individual's biography. Secondly, the notion of biographical disruption directs attention to the extent of work required by individuals diagnosed with cancer. Research which focuses on explicating a single identity, or on overarching issues of meaning, may miss the scale of the detailed and often distressing work across a wide range of identities, which is required in the re-negotiation of life with cancer. Indeed, as Mathieson and Stam (1995: 284) suggest, identities can be seen as "the vehicle for making sense of, not just an illness, but a life".

In dimensionalising the wide-scale nature of change in identities following cancer, this study reinforces recent research which suggested that cancer should be considered as a chronic illness. Early studies of biographical disruption focused on illnesses such as multiple sclerosis (Robinson, 2010), diabetes (Kelleher, 1988) and rheumatoid arthritis (Bury, 1982). However, Hubbard, Kidd and Kearney (2010) have argued that cancer should not be seen as an acute disease whose impact ends with completion of treatment, but rather as a disease which has an extensive and ongoing impact on individuals' lives. This view is supported by issues of biographical disruption found in recent studies with persons with colorectal cancer (Manderson, 2005; Rozmovits & Ziebland, 2004). It is also reinforced by quantitative studies from outside the field, such as the survey by Ganz et al (1996) which described impact on personal and sexual identities which persists years after diagnosis. Moreover, it is important to note that the experience of biographical disruption in this study was reported by women with early stage (i.e. less advanced)

breast cancer, and therefore experience of change may not be straightforwardly connected to longevity of disease symptoms or disease staging. Instead, explanations of the biographical disruption experienced here may be more usefully linked to issues of context, as Carricaburu and Pierret (1995) have suggested. For the women in this study, disruption appeared deeply linked to the unusually young age at which breast cancer was diagnosed, and also to the particular significance of the disease of cancer itself: an issue which I will explore later.

Developing the theory of biographical disruption, Bury (1991) suggested that there are two main ways in which persons seek to normalise their identities. The first style of management involved efforts to keep pre-illness identities intact, through strategies of minimising or denying change brought about by a disease. The second style involved the development of altered identities, through incorporation of changes drawn from illness. These two broad categories of response have been echoed in other literature focussing both on the lived experience and cognitive processing of trauma (Charmaz, 1995; Breakwell, 1986; Janoff-Bulman, 1992). While styles in the management of identities were not an explicit focus on this research, these broad patterns of responses may help explain the different levels of change reported by some participants. The lower level of overall change in identities reported by Ursula and Rachel may relate to a desire to preserve their pre-illness biography, while the wider changes described by other participants may indicate their motivation to make sense of the illness through altering their self image. However, there is an alternative explanation for these differing responses. Studies of chronic illness (Carricaburu & Pierret, 1995; Pound, Gompertz & Ebrahim, 1998) suggest that biographical disruption is not a universal experience, and that the impact of illness may be affected by personal factors, such as previous hardship in life. While Rachel and Ursula did describe changes in many areas of their identities, the nature of the events in their personal backgrounds (not explicitly covered in this research) may have reduced the scale of change they experienced compared with other participants.

Finally, as previously mentioned, the notion of biography suggests the impossibility of separating the meaning of an event from its context. Bury

(1991) argues that there are two types of meaning to be drawn from chronic illness. The first are the practical consequences for the individual: how the symptoms and physical sequelae of disease are logistically to be managed in daily life. The second is what Bury terms the “significance” of disease. This relates to the particular connotations and imagery of a condition, and the way these connotations are reflected in the manner individuals perceive themselves, and understand others to be perceiving them. While there is inevitably some messiness between the boundaries of these two types of meaning, I believe that this idea of significance can be used to draw deeper understanding of the changes in identities described in this research. For these participants, the significance of cancer can be understood to relate to wider social discourses about control of the body. In his overview of research in the field of biographical disruption, Williams (2000) proposed that future studies should “pay greater attention to the timing, context and circumstances within which illnesses are ‘normalised’ or problematised’, and the manner in which identities are threatened or affirmed...” (2000: 62). In order to throw further light on the context of changes in identities in this study, I will therefore briefly review broader discourses about the control of the body. Discussion will then consider the nature of biographical disruption in each of the main super-ordinate themes, with attention to the ways in which participants’ experience within each theme is shaped by the presence and use of these discourses.

4.2.2 Linking biographical disruption to the control of the body

In her extensive survey of the way the body is perceived in medicine, Lupton (2003) argues that, in Western societies, the body does not usually come into conscious being unless illness or pain is experienced. However, as I have discussed elsewhere (Nelson, Smith & Nicolson, 2010), such separation of mind and body inherent in our common practices become problematic when a person experiences illness. In such instances, it becomes clear that the body is the foundation of changes to identities; that it is “our general medium for having a world” (Merleau-Ponty, 1945/62:169). Recent scholarship has become increasingly interested in this social aspect of embodiment, and the ways in which a body is not merely a given reality, but a product of certain kinds of knowledge and discourses which are subject to change.

As Foucault (1980) proposes, the body can be seen as the site of political and ideological control. Through educational, legal and medical systems, a state can define the limits of behaviour and prescribe procedures for those bodies deemed to have violated established boundaries. In particular, Foucault (1979) challenged the status of medicine, arguing that it was not simply an objective set of scientific practices, but rather a major institution of power through which bodies are labelled as deviant or normal, as controlled or needful or control. The requirement for discipline of the body is notable in discourses of public health, where “the body is regarded as dangerous, problematic, ever threatening to run out of control, to attract disease, to pose an imminent danger to the rest of society” (Lupton, 2003: 33). Whereas public health concerns previously focused on the containment of infectious disease, Lupton (95; Peterson & Lupton, 1997) argues that attention has now turned to exhorting individuals to take responsibility for their own bodily health. This “privatisation” of health has had a number of consequences. Firstly, there has been an increasingly emphasis on the link between “life-style” diseases and associated behaviours, where the responsibility for disease is, at least partly, turned back to the individual. Secondly, in promulgating the view that health is a universal right, public discourses demand changes in behaviour and an awareness of risk which mean that – as Lupton (2003) argues – self control of the body has become the new work ethic.

This widespread discourse of self control of the body is taken up and used by all participants, in consideration of the changes they experience in their identities. In the following sections, I will explore particular manifestations of this wider discourse. When constructing and reconstructing embodied identities, a person works creatively with the social discourses which are available to her in her cultural and historical setting. As Gillies et al (2004) describe, in many instances these discourses can be seen as functional, enabling individuals to craft identities which are helpful in achieving a particular outcome. However, discourses may also be seen as restrictive, in that they constrain an individual’s potential identity. While I find the “functional/restrictive” nomenclature to have an uncomfortably judgemental

tone, the distinction has utility in clarifying the possible impact of particular uses of discourse.

4.2.3 Biographical disruption and challenges to embodiment

As previously discussed, illness – especially chronic illness – is an experience where the structures of everyday life, and the forms of knowledge underpinning them, are disrupted. In line with Bury (1982) and the wider literature, the experiences described in this research indicate that the physical state is the starting point for biographical disruption, through “the alteration of bodily states not usually brought into consciousness” (Bury, 1982: 169). In the first super-ordinate theme of “Challenges to embodiment”, it is apparent that for younger women with breast cancer, these altered states can include alienation and disconnection from their bodies, reappraisal of the relationship between body and mind, and a re-assessment of the way their physical appearance fits with their conception of the self. In this way, as Williams (2000) suggests, disruption may be seen as a transition from normal phenomenological modes of bodily “disappearance” – parallels are drawn to Sartre (1948), and a body which passes by in silence – to a state of corporeal “dys-appearance”, where the body’s presence becomes an issue through its problematic nature.

To consider the problematic nature of the body in more detail, we need to turn to individual subordinate themes of embodiment raised by this study. Stacey (1997) proposes that, although other illnesses can be deadly and painful, few carry the connotations and dread of cancer. This sense seems to be captured in the identity changes described in the subordinate theme “Something alien in my body”. In managing their new physical state, participants make use of vivid imagery to portray cancer as something foreign and hostile to themselves: a dangerous and evil predator. To cope with this predator, a military struggle is required; in this struggle, participants personify both the cancer and also the body parts affected by the cancer (“it”, “the boob”). This experience of cancer as the enemy has been documented in other clinical studies (e.g. Charmaz, 1995), and research into chronic illness has confirmed the frequent use of processes of disembodiment, where the disease is separated from the self

(Breaden, 1997; Bury, 1982; Finlay, 2003). Frank (1991) has suggested that we can make sense of this use of personification by seeing it as a human response in coping with something we don't fully understand. The still-uncertain origins of cancer leave it open to the mythic imagery of monsters and evil, because it cannot be biologically accounted for. Thus, as Sontag (1991) argues, the presence and use of such images can be seen as society's need to organise a chaotic, frightening world. By personifying the evil cancer, we draw boundaries around ourselves and attempt to control an apparently random disease. To the same end, the use of military imagery is linked to this idea of control, suggesting that the individual is involved in direct action against the disease and refuses to give in. Such implied dualism of mind and body, and disaggregation of body parts, are also represented in medical discourses. In her review of patient literature, Davis (2008) describes how breast cancer is portrayed as a frightening, deadly being. In discussions about treatment, women are not represented as three-dimensional human beings, but rather presented as the physical setting for cancer, with their body broken down into component parts.

Participants' sense of disconnection from their bodies, and the attribution of evil personhood to cancer, can thus be seen to draw upon wider social discourses. In many ways, use of these discourses can be seen as functional. By constructing the cancer as a separate entity, Cassell (1976) argues that it is possible to see the disease as something separate from oneself, and therefore one can retain the previous integrity of personhood once the cancer has been removed. This is indicated in this research by the change of heart mentioned by participants such as Ursula following surgery. The disembodiment implied in the construction of hair or breasts as "it" may also help women adjust to the distress of losing parts of their previous selves. Sartre (cited in Glover, 1987) described how, in his own experience of illness, he was aware of re-drawing the boundaries of the self, and in this study women's actions may enable them to lose the "Other" and consolidate their new embodied personhood. Finally, metaphors of mythical monsters and military campaigns may enable women to focus attention on gathering resources needed to achieve a particular goal.

However, there are also important ways in which these discourses may be restrictive. Goffman (1963) has argued that stigma arises from the perception of a dangerous or discredited attribute, and despite participants' work to distance themselves from this aspect, the use of such vivid imagery both by participants and the wider society may leave a sense of faulty personhood. In this way, I perceive that this initial imagery of cancer might be considered as the "primary stigma", while the changes wrought by treatment for cancer might be conceived of as "secondary stigma". As I shall discuss later, this sense of a tainted, stigmatised body, drawn from constructions of cancer as evil and alien, constrains the re-creation of other identities. The discourses may be restrictive in a further sense, in that they suggest a control which is not in fact possible. Cancer may be to some degree conceptually contained through personification, and the impact of bodily changes minimised through disembodiment practices. However, medical and social discourses of the body as controllable come into conflict with existential and phenomenological realities. For example, the later acknowledgement of issues of mortality suggest that participants are aware of this limit to control, while Nina's description of different sensation in her reconstructed breast indicates how medicine cannot return her body to what it was.

In the second subordinate theme "Just me in a body", identity issues also appear to relate to control and dualism of body and mind. Participants described the way in which cancer treatment left them feeling exhausted, reduced to a body. This state was likened by some to being old, in contrast to their chronologically youthful age; however, while many perceived fragility, one woman talked of perceiving a greater strength in her body through its capacity to withstand cancer. In her account of medicine as culture, Lupton (2003) depicts the way in which Western concepts of mind-body dualism and individual autonomy are intimately bound up in the bio-medical practices and discourses, which propose the body as something which is separate from, and capable of control by, the mind. However, what participants appear to be wrestling with here is the limitation of these discourses of control and autonomy. As Saywell, Henderson and Beattie (2000) argue, the experience of cancer can violate the normal boundaries of existence, creating a haziness around the extent to which body is constitutive of mind, and the degree to

which the subjective self is in control of the objectified body. The limits of the body may be seen as particularly difficult to reconcile for younger women. Many participants in this study remarked on the apparent incongruence between their "health", as signified through their previous practices in sports or at the gym, and the diagnosis of cancer. More positively, Lesley's sense of self appeared to have been enhanced rather than reduced by her bodily experience of cancer, through her perception of increased physical resilience. Thus in many regards, the dualistic discourse of a separate mind and body might be seen here as restrictive, in that it fails to capture the women's experience. Indeed, as Frank (1991) proposes, perhaps what illness teaches is the profound unity of mind and body.

In the final bodily identity, participants dwelt upon changes relating to their appearance. Breast cancer had resulted in surgery to the breast for all women, while many experienced side effects of further treatment such as weight gain and hair loss. Many women seemed to interpret this change through a discourse which Lupton (2003) calls the "commodified body". Here, good health is merged with sexual attractiveness, which may in turn be linked with a body that can be successfully "marketed" to prospective partners. Youth and specific forms of beauty (slenderness, number and shape of breasts) constitute socially accepted norms, while bodies which do not conform are seen as visually and conceptually out of place. Within this research, Gilly measures her satisfaction with her reconstructed breast through her continued ability to display herself in a bikini, while Nina's comments about feeling more "presentable" after breast augmentation suggest that she feels an enhanced ability to meet these social norms. Therefore, on one level new reconstructive techniques appear to allow women to choose to change their body, to maintain fit with such discourses.

However, on another level, such social discourses – and the reconstructive techniques which support them – may be seen as restrictive. Reconstruction aims to re-make the body so that it can "pass" as in keeping with socially prescribed norms, rather than challenging hegemonic conceptions of how the female body should be. This becomes a particular issue when changes to appearance cannot be concealed: issues of stigma which Goffman (1963)

describes as the discredited – as opposed to the potentially discreditable – body. Louise relates her sense of her discredited appearance, following her weight gain and loss of hair. Her phrase “you have to be” links with observations about the way a commodified body is associated with inner qualities. Bordo (1990) suggests that aspects of appearance such as slenderness and body tone are equated to moral qualities such as control, self-discipline and caring about the self. Thus the restrictions inherent in discourses of the commodified body can be seen to rest ultimately on previously discussed issues of bodily control and the limits of individual autonomy. An alternative discourse suggests different possibilities. In choosing to see her body’s altered appearance as “natural”, Lesley appears to associate her body with what Coward (1989) has described as the powerful symbolic meanings of wholesome-ness, integrity and goodness. “Not messing with nature” involves constructing identity differently: viewing continuity not through the preserved or controlled shape of the body, but through the accommodation of change.

4.2.4 Biographical disruption and negotiation of social roles

Describing the ways in which biographical disruption can affect mobilisation of social resources, Bury (1982: 169) suggests that illness brings “individuals, families and social networks face to face with the character of relationships in stark form, disrupting the normal rules of reciprocity and mutual support”. This was evident in the wide-ranging nature of change in social roles which was reported by participants in this study. As studies of biographical disruption have indicated (Hubbard, Kidd & Kearney, 2010; Wilson, 2007), these changes are driven both by functional limitations – physical and psychological difficulties in fulfilling social roles – and also by something which Bury (1982) terms “embarrassment”, but which I shall here call “stigma”. In the following discussion, I shall address the research question by focussing on important overall conclusions concerning changes in role identities, before moving to consider discourses of stigma which run across experience in all identities.

In reflecting upon altered identities following cancer, it is notable that participants spontaneously saw themselves in terms of roles which pre-existed cancer, rather than in the acquisition of new roles. In describing change,

participants described disruption to the content and values of existing or latent roles such as partner-mother-friend, but did not voluntarily cite illness identities such as patient-survivor-victim, which are often the focus of psychological research. This runs contrary to quantitative studies assessing cancer “survivorship”, such as the surveys of cancer survivors by Deimling, Bowman and Wagner (2007) cited earlier, which proposed that that 86% of the sample identified as a survivor, with 42% self-identifying as an ex-patient and 13% as a victim. The different findings in my study may simply relate to issues of sample size, or to national differences in the American population of the aforementioned study. However, failure spontaneously to claim “survivorship” may also be seen as supporting the arguments of Kaiser (2008), confirming the sense of the survivor identity being driven by medical professionals rather than emerging from women’s experience, where issues of survival had complex meanings. From my findings in this research, I would support Kaiser’s proposal that, to be useful to people with cancer, ongoing promotion of the survivorship identity within health research needs to encompass more nuanced issues of fear, and to address stigma linked to an ongoing association with cancer.

Within the changes observed in pre-existing identities, there appear to be a number of important patterns. Firstly is the importance ascribed to intimate relationships, such as partner-mother-friend. Many studies have documented how – in line with general findings in other areas of psychology – social support is both valued and associated with greater psychological wellbeing throughout the experience with cancer (Lethborg, Aranda & Kissane, 2008; Waxler-Morrison, Hislop, Mears & Kan, 1991). These changes can be explained in many ways. Following the arguments of Jordan (1991), it is possible to see the centrality of these identities as a sign of women’s more relational sense of self, where both the giving and receiving of support is valued. For example, in her study of biographical disruption of women with HIV, Wilson (2007) describes how motherhood provides an important source of continuity, purpose and self-worth when coping with chronic illness. Many of the women in this study describe attributing new value in such a way, while also wrestling with the practical difficulties of the role of wife or mother. A further explanation for these changes may lie in a greater awareness of their own mortality, which, as

May (1983) discusses, can lead to a greater appreciation of connections with others.

However, the focus on younger women in this research indicates how cancer during this life-stage may cause particular issues regarding roles which may already be perceived within our society as 'deficit identities' (Reynolds & Taylor, 2005). Disclosing the physical changes caused by cancer, and relating the practical consequences of breast cancer for fertility, puts a potentially higher strain on any new partnership, thus increasing the already difficult task of managing 'singleness' which Reynolds, Wetherell and Taylor (2007) describe. Moreover, this difficulty may be amplified by ongoing cancer treatment which denies the possibility of being a mother. Existing research (Steinberg; 1990; Strickler, 1992) has suggested that women perceive infertility as a loss of control over their bodies, and experience grief both for the child they never had and for their misalignment with social expectations of motherhood. Issues of infertility following cancer are often more problematic for women than for men, as procedures to harvest eggs are more invasive and time-consuming than the banking of sperm, and cancer treatment rarely allows time for such considerations. This research suggests that the individual and cumulative weight of such losses needs to be recognised and taken into account in the care of women with breast cancer. Similarly to Grinyer (2007), who explored the impact of cancer in the teenage years, my findings indicate that a person's age and gender mediate the experience of illness and the forms of biographical disruption.

Finally, this research has drawn attention to two other identities which have especial significance for younger women, but which have received surprisingly little attention in research: the roles of friend and work colleague. Given the existing literature concerning both on the impact of unemployment (Jahoda, 1979; 1981; 1982) and on issues of employment related to other chronic illnesses (Bury, 1982; Rozmovits & Ziebland, 2004), the omission of more detailed research into work identities appears an important oversight. This study accords with research from Johnsson, Fornander, Rutqist and Olsson (2010) in highlighting the importance of managing issues of social support and co-workers' attitudes in the return to work of women with breast cancer;

however, it also raises additional questions concerning employers' discriminative practices reported in the maintenance of these work identities.

Similarly, given the known importance of social support to psychological well-being and cancer, it is surprising that there are not more detailed examinations of the interaction between friendship identities and cancer. This research has briefly outlined how breast cancer brought many changes to women's experience of friendship, both in terms of the increased appreciation of the practical and emotional support of close friends, but also in terms of difficulties in communication and in the management of negative, discriminatory reactions. Research within the field of biographical disruption indicates that these changes are not unusual. In their study of biographical disruption following an HIV-diagnosis, Carricaburu and Pierret (1995) briefly mentioned that gay men perceived their relationships with friends to be of greater importance, and this was reflected in the frequency and intensity of meetings. In her consideration of the biographical disruption of teenage cancer, Grinyer (2007) also touches upon issues of friendship; she describes how participants feel isolated from their peers due to their unusual physical state, and suggests that within the expectance of sociality at this life-stage, ongoing and enforced isolation due to cancer can be particularly demoralising. However, detailed consideration of the lived experience of friendship and breast cancer is currently lacking.

Within each role identity, and for each participant, the issue of the stigma has appeared in some form. The stigma of cancer is intimately related to discourses of self-control and the body; as previously discussed, the original "mark" of this stigma appears to be a body which is dangerous, uncontrolled and tainted, both through contact with an "evil" disease and through the bodily changes effected by cancer. Stigmatising discourses and practices are implicated in difficult movement in all role identities. As Charmaz (1991) describes, the shame and suffering in such changes derive both from the person's own sense of failure in meeting internalised social standards, and also from the behaviour of others acting from those same standards: aspects of stigma captured by Scambler and Hopkins (1988) as "felt" and "enacted". As a mother, Zoe described her guilt at potentially inflicting breast cancer upon her

daughters; in this instance, the felt stigma of an uncontrollable body appears also to relate to social standards in another discourse of “good mothering” (Elmberger, Bolund, Magnusson, Lutzen & Andershed, 2008). As a prospective partner, Rachel stated that she perceived she would be less desired, both inherently and because of potential difficulties with childbearing. Here, the felt stigma of a tainted body seems to connect up with the discourse of the commodified body, as mentioned earlier. In work, Louise and Lesley describe experiencing direct discrimination as a result of their breast cancer, while Gilly decides to keep her experience of cancer secret from her employers. This stigma, both enacted and felt, implies that the new – reduced – status of their bodies makes them less valuable as employees; in this instance, control of the body seems strongly linked with dominant discourses of productivity (Sennett, 1998). In social settings, Louise and Zoe describe the sense of shame at their altered appearance; in addition to this felt stigma, there were instances of enacted stigma, such as Becky’s sense of exposure when her disclosure of cancer was not comfortably received by another.

Self-evidently, the stigmatising discourses of cancer were restrictive at some level for all women. Furthermore, it was my perception that a substantial proportion of the difficult changes in role identities experienced by these participants involved issues of stigma. Participants actively managed their positions, using many of the strategies which Goffman (1963) outlined. Life was rearranged to avoid awkward contact at work; body changes or the fact of cancer itself were concealed, with the aim of “passing as normal”; communication of cancer was restricted to a small group of intimates, while wider contacts were told nothing. There were other strategies which aimed actively to resist the sense of stigma, by challenging disclosure etiquette and sharing the experience of cancer. Both Lesley and Nina talked of seeking opportunities to present publicly their own experience, with the aim of normalising breast cancer. However, despite the active and productive strategies used by all participants, I was left at the end of this research with a deep sense of sadness that the stigma of cancer – the uncontrollable, tainted body – remains so prevalent and so powerful. I had considered that increased media discussion of breast cancer issues might have lessened this sense of stigma. Yet the accounts in this research suggested an alternative outcome:

that the heightened importance accorded to self-control of the body may have outweighed any benefits from greater public awareness. As Sontag (1991) and Frank (1991) have argued, we still appear to hold moralised notions of disease, where both the individual's competence (Why me? Why her?) and value to society can be called into question. This links with changes in emotional-existential identities.

4.2.5 Biographical disruption and emotional-existential identities

If challenges to embodiment disrupt understanding of the form of personhood, emotional-existential identities are the place where participants try to make sense of their disrupted relation to life itself. As Bury (1982: 169) proposes, chronic illness can result in "profound disruptions in explanatory systems normally used by people, such that a fundamental re-thinking of the person's biography and self-concept is involved". Frank (1991) suggested that medical talk during cancer focuses on the part which is breaking down, while ignoring the frequent breaking down and re-making of the whole person: what has been described elsewhere as the modification of "being-in-the-world" (May, 1983). In reviewing individual identities, this section will examine to what extent participants found coherence in their altered sense of mortality, in their emotions of fear, frustration and loss, and in the meaning of being ill. It will also consider how the discourse of self-control is implicated in these meanings.

In facing their own mortality, participants perceived a profound shift in their relationship to death. Bury (1982: 171) has described how a chronic illness such as arthritis can bring about a sense of premature ageing: a "biographical shift from a perceived normal trajectory through relatively predictable chronological steps, to one fundamentally abnormal and inwardly damaging." This seemed to be reflected in several comments in this study, where women described feeling much older, or viewing their previous orientation to life as that of a child. In contemplating – at least briefly – the possibility of their own death, women's sense of their position on the trajectory of life had changed, perhaps through an awareness that assumptions of a normal life-span might not apply to them. Such experiences link with aspects of biographical disruption described by Hubbard, Kidd and Kearney (2010), where a cancer

diagnosis also brought to the fore participants' sense of their own mortality and death.

Prominent in participants' consideration of their mortality are references to fate. Accounts dwell on the fragility of the life, and on the randomness of existence: the flipside of a coin; being lucky; being a cat with nine lives. These images can be read on a number of levels. One interpretation might be to see participants actively challenging discourses which propose that individuals can and should control their bodies. In arguing for the decisive role of fate, participants are resisting implications of personal failure and lack of attention to their health, by proposing that cancer and death are in many respects a matter of luck. This point is explicitly raised by Rachel, who questions the extent to which diet and exercise can affect cancer incidence. Recent research by Lupton (1995) and Prior (2000) discussed how public health discourses claim that taking prescribed measures will protect against early death. A corresponding response from individuals with cancer may be to resist ideas that death is preventable and within their control. This may be particularly significant for the younger women in this study, where the unusually early occurrence of cancer might add particular emphasis to the question "why me?"

However, participants' invocation of fate can also be seen to challenge discourses of bodily control in another way. Frank (1991) has argued that we seek to promote beliefs in control, as they are a way of containing and constraining the inherent riskiness of life. Yet as writers such as Camus (2006) have suggested, the nature of our existence may be alternately seen as one where events are often random, and our control over our bodies is at very best partial. In crafting these new views on mortality, participants may therefore be seen as re-building their assumptions about the nature of the world. In her work on changes following trauma, Janoff-Bulman (1992) considers how those who experience "natural disasters" such as environmental catastrophe or illness may experience difficulty in reassessing their beliefs about the meaningfulness of the world and the nature of justice: the degree to which an individual person's actions cause and merit a particular outcome. Participants' changed identities in this area may thus be seen as a functional response to the existential reality of their lives, and also a resistance to discourses which

might be seen as promoting an unreasonably high expectation from bodily control.

The changes which participants perceived in their autonomy were among the most moving for me as a researcher. I believe this was because I felt that participants were, in some measure, baring the vulnerability of their existence. In his discussion of existential ideas, May (1983) notes how Nietzsche employs terms like anxiety and fear not as clinical terms, but as signifiers of our wider ontological state. May argues that our particular existence – the 'Dasein' – is in a continuous and dialectical relationship with non-being. Seeing the emotions described by participants within this frame, awareness of individual strength (resilience in dealing with cancer) and vulnerability (fear of a recurrence of cancer, and losses experienced through cancer) can be seen as an appropriate recognition of the potentialities of a person's existence. I think it is significant that research within cognitive paradigms has also affirmed the significance of acknowledging vulnerability. Specifically, in their examination of meaning-making after trauma, studies by Tedeschi and Calhoun (1996) and Jim and Anderson (2007) found that awareness of vulnerability and meaning, rather than meaning alone, better predicts more benefit-finding after potentially traumatic life events such as a cancer diagnosis.

For these reasons, it might be argued that discourses of self-control of the body can inhibit functional responses to breast cancer. Participants' accounts in this study indicated two ways in which this might happen. Being positive – or what Lupton (2003:72) terms "the discourse of hope" – has been widely promoted as a significant factor in an individual's successful recovery from cancer. Control of the body is thus seen as a direct function of proper control of the mind, which is related to success in the military battle against cancer (Erwin, 1987). The validity of these discourses has now been comprehensively challenged, by psychological research which – in all but extreme instances – denies the connection between emotional states and cancer survival (Coyne, Stefanek & Palmer, 2007; Coyne, Toombs, Stefanek & Palmer, 2009). However, for many participants in this study, the fears and losses they experienced were often kept private, and as well as interpreting such decisions as a further reflection of the personal management of the stigma of cancer, it is possible to

conceive of these acts as a way of dealing with restrictive social discourses which deny or criticise the expression of vulnerability. As Ehrenreich (2009: 42) has argued, this “tyranny of positive thinking” acts to inhibit and privatise more “negative” reactions to cancer such as anger, fear and anxiety, construing them as implicitly shameful and “weak”.

The final emotional-existential identity might be seen as a summation of all the changes in identities which each woman had perceived: an existential “bottom line”. As such it is more difficult to relate to specific discourses of bodily self-control. However, in considering the theme ‘Following a different path to before’, it is possible to draw some overall conclusions about the nature of the biographical disruption experienced after breast cancer. For women such as Rachel and Ursula, individual changes in bodily and role identities were not linked to wide-scale change in direction of their life. Some researchers (Frank, 2003; Shapiro, Angus & Davis, 1997) have styled such responses to cancer as “Bump in the Road” or “Back to Normal”, and in some respects it may be arguable as to whether these women have experienced biographical disruption. If, as Bury (1982) appears to suggest, biographical disruption is viewed as wholesale change in identities across the three domains of body, social roles and explanatory systems, then it seems as if this term is not applicable to the experience of Rachel and Ursula. However, in my consideration of biographical disruption, I wondered whether it is more useful to see such changes not as categorical but as a continuum: that biographical disruption is better seen as a question of degree, rather than all-or-nothing change.

The accounts of remaining participants described extensive change, but of varying kinds. The work of Charmaz (1995) helps illuminate the nature of biographical disruption, and further refine ideas of the accommodative style of biographical management outlined by Radley (1989) and Bury (1991). Those women in this final identity who saw themselves as embracing life can be seen as *adapting* to cancer; their response to experience involves accommodating losses and reunifying the body and self through new, extensive projects. Women who observed a more ambivalent sense of change – lost dreams, a tainted appreciation of life – might be argued to be *reconciling* themselves to cancer. This response to experience involves working round changes arising

from their illness, but appears to place more emphasis on the restrictions which cancer has brought. However, in closing this consideration of styles of biographical disruption, I believe it is important not to be drawn into crude evaluations of relative utility. As Ehrenreich (2009) bluntly states, cancer is not a “makeover opportunity” (2009: 31). Instead, the diversity of styles might be seen as a sign of the creativity which individuals demonstrate in working with their different circumstances, personal histories and cognitive and other resources. This has implications for therapy, as I shall discuss below.

4.2.6 Conclusions about biographical disruption

As I have articulated above, I believe that the wide-scale change in identities generally documented in this study can be usefully viewed through the framework of biographical disruption. Previous research on biographical disruption (Hubbard Kidd & Kearney, 2010; Williams, 2000) has observed that the phenomenon cannot be assumed to apply to everyone who experiences chronic illness. Within this study, I have reflected whether the more limited change described by two participants meets current definitions of biographical disruption; perhaps, as I have discussed, the concept needs to be extended to encompass a more continuous – rather than categorical – evaluation of change. However, the extensive changes voiced by most women convey the challenges of living with breast cancer. As Mathieson and Stam (1995) have argued, identities are transformed by cancer, and research limited to evaluation of psycho-social variables is not capable of doing justice to the nature of this change. I therefore believe that the concept of biographical disruption can be a valuable way of dimensionalising, and communicating, the impact of cancer.

I have also sought to enhance interpretation of experience by considering how biographical disruption is informed by issues of context. As Radley (1989) noted, “what people adjust *with* is as important a matter as what they adjust *to*” (1989: 243). Guided by the material of participants’ accounts, I have chosen to consider how a particular aspect of context – social discourses relating to self-control of the body – is implicated in participants’ altered identities. Ashmore and Jussim (1997) propose that such public discourses

mediate between larger social arrangements and the creation of inner selves, in a dialectical process where individuals create and recreate the identities which form the basis for biography. In considering the interactions between discourse and the experience of younger women, my research adds to previous explorations of biographical disruption, which have paid greater attention to structural issues of class (Wilson, 1997) and age (Pound, Gompertz & Ebrahim, 1998).

In concluding this discussion of biographical disruption, I would like to take up an issue raised by Kelly and Field (1998). Following on from Giddens (1991), Kelly and Field suggest that chronic illness has become less disruptive in the modernist and post-modernist eras. Greater attention to deterministic social structures and the increased plurality in discourses is seen as enabling a more flexible adjustment to change. However, on the basis of this research, I would have concerns in taking such a benign view. Instead, as Williams (2000) has discussed, it is possible to argue that our society is creating alternative pathologies, through an excessive attention to the continual re-making and re-modelling of the self. Discourses of bodily self-control can be seen as one such instance of re-modelling. Furthermore, as Ehrenreich (2009) asserts, treatment for breast cancer remains a punishing and life-disrupting experience. Despite advances in reconstructive surgery for breast cancer, treatments such as radiotherapy and chemotherapy have remained very similar for the past three decades. Thus the exploration of continuity and change in identities following breast cancer - or biographical disruption - appears to merit wider and more sustained investigation.

4.3 Limitations of this study and opportunities for further research

This study has proposed an important connection between the lived experience of breast cancer for younger women and ideas of biographical disruption. However, the small scale of this research has not permitted more general conclusions about the breadth and nature of biographical disruption in breast cancer, or indeed across different forms of cancer. Moreover, in creating therapeutic support programmes, it would be important to know whether

different aspects of disruption link to particular distress or clinical issues. Therefore, this research can be extended by triangulating the phenomenon of biographical disruption and cancer, using a variety of methodological approaches. Kvale and Brinkman (2009) and Tindall (1994) discuss how survey techniques can be productively linked to qualitative methods such as diaries or interviews. This more comprehensive research programme might allow a quantitative measure of the degree of change in identities perceived by a larger sample of participants (people with breast cancer across all age groups; younger people diagnosed with a variety of cancers), while also gaining explanatory understanding of the nature of these changes. Completion of clinical measures of distress would enable the phenomenon of biographical disruption to inform development of therapeutic support, as discussed below.

The focus of this particular research can be seen as both a strength and a limitation. Examining the range of identities has allowed understanding of the breadth of change which women experience, and the practical and discursive challenges of managing this change. This has enabled me to make useful connections with the literature of biographical disruption. However, there is now an opportunity to follow up some of these less-explored identity issues in greater detail. Identities concerning friendship and work were notable both for the importance accorded by participants and for the challenges such identities presented. Future research could consider a new project examining friendship issues, or could amplify this study's research material through collaboration with the findings of researchers such as Hubbard, Kidd and Kearney (2010) or Rozmovits and Ziebland (2004).

Another limitation to this study is its cross-sectional structure. The rationale for the choice of a single interview within eighteen months of diagnosis has been articulated earlier. However, as Riessman (2003) has suggested within her critique of narrative approaches, "constructing 'who I am' is an ongoing activity with a limited range, context-specific, a practical project of everyday life" (2003:8). Therefore this study does not enable the researcher to understand whether the phenomenon of biographical disruption is temporary or permanent, nor to examine the impact of cancer on identities across time. Flowers (2008) suggests that planned multiple contacts can offer the chance to

probe and develop material from an initial meeting, and also to build a trusting relationship where participants feel comfortable with increased disclosure. However, he also cautions that one danger of such multiple contacts is that the focus can turn away from an open examination of lived experience at that time, and instead be dominated by “follow up” on issues raised previously. Therefore important consideration would need to be given to the forms of contact in a longitudinal study. One option might be to supplement interviews with personal video diaries or blogs, which might allow more spontaneous records of experience to sit alongside semi-structured techniques. While obviously time-consuming, implementation of such a longitudinal study might enable the creation of a stage or process model of biographical disruption, similar to those found in bereavement work (Stroebe & Schut, 1999; Worden; 1983).

The nature of findings in this study may have been significantly affected by the characteristics of its participant group. As Rozmarits and Ziebland (2004) indicate, it is possible that volunteers may differ from a broader sample in their motivation to be involved. Volunteers may be drawn to take part because of a particularly positive experience, or conversely a particularly difficult one. While it is obviously impossible for the researcher to be sure of such issues, I find some reassurance in the nature of the findings. The differing accounts of change and overall meaning described by participants suggest that there was not one motivation driving participation. Furthermore, in my conversations with participants during the de-briefing, the women raised a variety of reasons for their involvement in the research, from a desire to help other women and a sense of gratitude to the charity through which I recruited, to a need to have more time to understand their experience.

However, there are other characteristics of the participant group which may have had greater effect on the study’s findings. Previous studies have suggested that social class can have an important effect on the experience of biographical disruption. Specifically, research to date indicates that people from the middle classes are more likely to experience disruption than those described as being working class (Bury, 1982; Radley, 1989). This traces potentially to heightened middle class expectations concerning the nature of

identities, and also to previous experiences of disruption to health, work and family among those with fewer resources. An assessment of the educational and occupational status of this study's participants indicates that all participants might be viewed as middle class, and thus more likely to experience disruption. Similarly, concern might be raised over the participant group's ethnicity, as all women were of Caucasian origin. While there is little existing research in biographical disruption – and in cancer and identity – concerning the interaction of ethnicity with experience of cancer, it seems probable that such cultural beliefs and support structures affect the perception and understanding of breast cancer. In any further research, issues of class and ethnicity among the participant group would therefore be an important consideration.

Finally, this research has made me consider whether existing psychological research into cancer is avoiding “the elephant in the room”. Issues of stigma have been raised in many different studies of people with cancer, from research into biographical disruption to studies of identity (Mathieson & Stam, 1995; Rozmovits & Ziebland, 2004). However, despite having the pioneering work of Goffman (1963) and Sontag (1991) to light the way, there does not appear to be any recent research which has directly addressed this issue. Perhaps this is because the nature of stigma is hard to grapple with, given its roots in the wider social issues of group identities which Tajfel (1969; 1981) described, and its multiple manifestations at the intrapersonal, interpersonal and societal levels. Yet this complexity of the subject offers many opportunities for further research. Action research could be conducted, to consider how the stigma of cancer can be raised and alleviated in the workplace. Discourse analysis could update the work of Saywell, Henderson & Beattie (2000), and consider whether media representations of breast cancer have altered within the past ten years. Discourse techniques could also be used to analyse the constructions within UK patient information for cancer, and consider whether these contribute to the sense of stigma. Finally, researchers across a range of chronic illness could combine resources to explore how issues of stigma are experienced, and to identify ways in which this stigma can begin to be addressed.

4.4 Implications for counselling psychology

The thought-provoking discussion by Strawbridge and Woolfe (2003) of the nature of counselling psychology has helped me formulate two principal ways in which professional considerations intersect with this research. The first involves consideration as a scientist-practitioner of the ways in which issues of biographical disruption might be addressed in a therapeutic context. An important initial question might be a decision as to whether therapy is necessary for those experiencing cancer. While biographical disruption involves difficult and often distressing changes, perhaps it might be more useful to see it as a life experience similar to bereavement, where change is mostly accomplished without professional intervention (Parkes, 1996). A consensus between the two fields is suggested by recent research by Coyne, Stefanek and Palmer (2006) and Nezu, Nezu, Felgoise, McClure and Houts (2003), which indicates that therapeutic interventions in cancer have greatest impact among those assessed to be in greater distress. This parallels recent directions in bereavement research, where studies have indicated that therapy appears to effect greater change among those in more complex – and often more distressing – situations (Parkes, 2006; Stroebe, Schut & Stroebe, 2007).

However, there may be an alternative way of viewing the provision of therapy after cancer. Woolfe (1990) reminds us that, in addition to working with psycho-pathology, counselling psychologists can play a wider role in the facilitation of mental and physical well-being. To this end, it is interesting to note that the majority of participants in this research expressed a sense of fulfilment from the opportunity to describe their changed sense of self. Louise said that she had “searched for things deep down, and said things I’ve probably almost tried to hide” (69:27), while Becky observed that “this has been cathartic in a way [...] drawing a line and saying, right, that’s it” (56:14). Nina commented that the interview had enabled her to “find things out about myself that I didn’t know by talking about them in such detail, so I got quite a lot out of it” (52,2). These benefits appear desirable in and of themselves, and suggest that provision of individual or group therapy beyond the narrow focus of clinical distress can be valuable. In the debriefing following my research, participants suggested that therapeutic support would be particularly helpful at

two stages. Following the diagnosis of cancer, many participants observed they would have benefited from greater information about the treatments they were to undergo, as well as from an opportunity to meet other women and to “normalise” the fears and emotions they were experiencing. At the end of treatment, several participants commented that a “cancer rehabilitation” would have helped them prepare for re-entry back into their working and social lives.

There is some interesting research which might support the wider provision of support, on the basis of broader health-related criteria. Evidence from Simpson, Carlson and Trew (2001) and Rosenberg, Rosenberg and Ernstoff (2002) indicates that group psychological interventions for cancer patients with lower levels of distress resulted in decreased use of health care services and improvements in the domains of physical symptoms, and was thus a viable financial proposition. Therefore as Carlson and Bultz (2004) argue, any review of the efficacy of psycho-social interventions may need to consider the whether evaluations of therapeutic support should be restricted to psychological measures, or should assess the wider impact of psychological care.

Turning to specific therapeutic modalities, this research cannot add meaningfully to recent reviews of psychological interventions, such as those by Cunningham (1995; 2000), Meyer and Mark (1995) and Coyne, Stefanek and Palmer (2007). However, the predominant therapeutic approaches indicated by the evidence in these studies (supportive/person centred and cognitive-behavioural therapy) would each appear to address issues at stake in biographical disruption, such as conditions of worth and rebuilding of assumptions and beliefs. Interestingly, recent developments in cognitive therapy have seen a move away from identification and modification of coping styles (Adjuvant Psychological Therapy: Moorey & Greer, 1989) to consider the socio-cognitive aspects of personal transition (Brennan, 2001). Within this approach, it is possible to consider how the “Who Am I?” research tool could be modified and evaluated as an additional screening device, with the aim of rapidly assessing wider aspects of biographical disruption. Thinking more widely, the nature of biographical disruption described in this study suggests that the value of narrative and existential therapies should be more rigorously explored. While narrative therapy has been used in many health care settings

to assist in rehabilitation from conditions such as heart disease, it is difficult to obtain robust studies of its use in cancer. Similarly, existential approaches to meaning-making have been documented for end of life care (Breitbart, Gibson, Poppito & Berg, 2004), but there has been little evaluation of its use at earlier stages of cancer.

Review of approaches to therapy is useful and has its place. However, Strawbridge and Woolfe (2003) challenge us to think more imaginatively about the role of counselling psychology. Quoting Pilgrim and Bentall (1999), they ask us to envisage a profession where “the study of psycho-pathology itself is replaced by a study of the ways in which psycho-pathology is represented or socially constructed” (Strawbridge & Woolfe, 2003:18). This particular research suggests two possibilities for wider action by counselling psychologists. The first relates to the discursive construction of illness and disease. Frank (1991; 2003) has been notable for his extensive work to challenge existing conceptions of illness. Decrying the excessive attention to bodily self-control in current discourses, he argues that we need to place a higher value on illness. Conceiving that health and illness are foreground and background in our life-worlds, valuing illness restores a sense of proportion lost when life is taken for granted. Our creativity and our frailty are profoundly linked, and through illness we can better understand the nature of our existence in the world, and our connection with others.

While Frank – by training a sociologist – has worked actively to change conceptions of illness, there is a conspicuous absence of psychologists working on this wider level. Counselling psychologists could work towards change in a variety of ways – workshops, papers, seminars – but perhaps one of the most wide-reaching could be the use of popular media. The opportunities are apparent in the recent contrasting presentations of different medical conditions. At the time of writing, one woman’s experience of a mastectomy is being reviewed in a television programme entitled “Embarrassing Bodies” (Fraser, 2010). Although the programme purports to alleviate embarrassment over medical conditions, its title hints at “freak show” qualities, and indeed criticism of the programme has centred on whether it builds – rather than challenges – stigma. Alternatively, a national newspaper currently

runs a weekly column from a woman who has experienced extensive spinal injuries (Reid, 2010). This page documents her lived experience, and, in my judgement, allows readers to understand the nuanced emotional and practical issues involved in living with this condition. In the normalisation of illness, I believe there is space for more of the latter kind of account. Rather than seeing ourselves as limited to the consulting room, counselling psychologists could consider whether to work with media partners to create more sensitive – rather than sensational – accounts of illness.

This links with my final comments, which concern ways of dealing with the stigma of cancer. While stigma can obviously be worked with at the individual therapeutic level, counselling psychologists may have greater leverage when working at the wider societal or organisational levels. This may involve becoming involved with institutions where there is an opportunity to influence models of care, patient literature, or employment and social practices: hospital boards; campaigning or charitable organisations such as (in this instance) Breast Cancer Care or Breast Cancer Haven; a co-operative workplace. As previously described, it may require us to pay direct attention to the issue of stigma in research. Perhaps it has been easier to turn away from the difficult issues raised by stigma in cancer, rather like some of the social contacts of participants in this study. However, consideration of the more vocal and high profile campaigning work among persons with HIV (Woodward, 2000) may point to the value of a different strategy.

4.5 Final questions of reflexivity

The close of this research brings an end to the “dialectical dance” (Finlay, 2008: 3) of reflexivity, whose beginning was discussed within the Methodology chapter. As the research has moved towards completion, I have developed greater understanding of the processual nature of reflexivity, and the ways in which I have shaped, and been shaped by, the material in its final chapters. Following my earlier use of the ideas of Wilkinson (1988), I would like to extend my previous comments on reflexivity by further exploration of personal, functional and disciplinary issues.

Turning first to functional issues, I have become increasingly aware of the ways in which my personal convictions as a researcher have influenced the nature of findings in this research. My decision to focus on the whole gamut of identities experienced by participants was driven by my personal experience of cancer, my work with clients, and by analysis of the research literature. However, in many ways, the scale of this work was a rookie's mistake. This became clear as I struggled with page after page of detailed and thoughtful comments from my participants. My sense of being overwhelmed by data was exacerbated by the new interview approach I devised for this study. The "Who Am I?" tool proved extremely effective in gathering highly relevant information which directly conveyed participants' own understanding of their experience, unmediated by my pre-conceptions. It also appeared to be well-received by participants, who suggested that "if you had just set questions...it's not so deep coz you didn't write them yourself" (Louise: 69,13). However, this resulted in descriptions of a phenomenon which was far wider than I had initially conceived. My first research interview guide (Appendix 2) shows how my early ideas of identity were largely limited to roles; however, participants' own responses indicated that embodied identities and emotional-existential identities were vital parts of their experience. This wealth of material provided plenty of opportunity for individual research presentations (Nelson, 2010; Nelson, Smith & Nicolson, 2010), but caused me to spend hours sequestered with tiny print-outs of quotes, as I attempted to build up a picture.

During the analysis and discussion, I spent many hours in the hermeneutic circle moving between the part and the whole, as Smith, Flowers and Larkin (2009) suggest. Within the analysis, one of the more difficult pieces of work was the composition of the emotional-existential super-ordinate theme. Originally envisioned as simply "emotional identities", the subordinate theme "Following a different path" was originally a separate super-ordinate theme. However, with the use of abstraction I began to understand how these seemingly disparate parts might fit together as a larger whole. Within the discussion, consideration of the part and the whole involved an assessment of the way my findings fitted within broader frameworks of life change. My ultimate alignment of the phenomenon of changing identities with biographical

disruption was not something I had envisaged at the start of the study, although I now feel that the concept is very well suited to the accounts of participants. Thus, from a functional perspective, this experience has highlighted for me the importance of creativity with research tools to enhance the quality of data gathered. It has also highlighted the importance of being open to the data, and working outwards from the data to theory. I am aware that my personal background and interests have inevitably affected the possible interpretations I might have made of the data; for example, my professional and personal experience made psycho-dynamic analyses less accessible than constructionist approaches. I am also mindful that - as Riessman (2003) has highlighted - a researcher's understanding of interview material can change across time, with her altered experience and insight. However, within this inevitable subjectivity, I have been conscious at each stage of trying to find ways in which any interpretations are rigorously grounded in the material of participants' accounts.

On a personal level, I have found myself partly following the trajectory of Le Gallais (2008), in her move from insider to outsider. When I conceived of the study, my own experience with breast cancer was very much in the foreground, and as I described earlier, this influenced both my research aim and my choice of methodology. Yet as the work progressed to its conclusion, I felt an increasing responsibility to do justice to these women's interviews: that it was their story, and not mine. This has led me to reflect on key aspects of the findings. I had not conceived of the totality of my own experience as biographical disruption, nor been aware of the impact of stigma or the relevance of discourses of bodily self-control. Therefore, as Moran (2000) suggests, I could feel confidence in my findings, in that I could perceive that the processes of bracketing and practices of reflexivity meant that the data had not been forcibly fitted to pre-existing patterns.

Yet, while perceiving myself now to be more firmly situated on the outside, the study's findings have also given greater coherence to my personal experience. For example, I can understand the value of my yoga practice in providing me with alternative conceptualisations of mind and body from those provided in medicine. My location within the profession of counselling psychology not only

facilitated personal processes of meaning-making, but also provided colleagues and settings that accepted and worked with my cancer treatment. At times, the accounts from participants touched identity challenges in motherhood or friendship which I recognised from my own experience, and I am also aware that the theoretical reading for this study has often helped me understand my own life positions, in addition to those of participants. However, to a large degree, I believe this relates to the unavoidable intersection between the personal and professional in any work as a psychologist. At the close of this study, my sense is of a project which has been originated and framed by me, but where the strong, passionate, and often unexpected voices of the women participants predominate. The perception of my changed status in this work has led me to alter the research's title. Instead of the oblique reference to my own experience in the earlier "Cancer and 'Me'...", I have now chosen the less personal "Cancer and biographical disruption...".

Finally, completing this study has re-connected me with disciplinary concerns which had become somewhat obscured by my focus on clinical counselling psychology practice. In my early reflexive writings, I was clear that the personal was the political: my personal experience with breast cancer inspired me to conduct research which voiced other women's experience of breast cancer. However, in my reassessment of possibilities as a counselling psychologist, I am now assessing how the personal can become political, in a wider sense: how I might build from my new understanding of illness and stigma derived from the personal experiences of women in this research, to influence political change within organisations, institutions or social settings. To this end, I have found inspiration from psychologists such as Higley and Milton (2008), who have engaged counselling psychology with broader environmental issues outside the traditional mental health contexts. While I continue to be drawn to therapeutic work, I am considering how I might draw new inspiration from community psychology, and work more directly for social change.

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Appendices

Appendix 1: Glossary of cancer terms

Chemotherapy:	Chemotherapy is the use of anti-cancer drugs to destroy cancer cells around the entire body. It is given if it is believed that cancer cells may have spread beyond their original site. These drugs are given by injection into a vein or as tablets. There are many different chemotherapy drugs, with different side-effects. Chemotherapy is usually given as an outpatient, and a complete course may take 4-6 months. Side-effects can include nausea and vomiting, lower resistance to infection, anaemia, sore mouth, and poor appetite, as well as hair loss and fatigue.
Lumpectomy:	This surgical procedure involves removal of the breast lump, together with some surrounding tissue. A lumpectomy is usually followed by radiotherapy treatment to the remaining breast tissue. It removes the least amount of tissue, but leaves a small scar and sometimes a small dent in the breast.
Mastectomy:	A mastectomy is a surgical procedure which involves removal of the whole breast. It may be necessary if the breast lump is large in proportion to the rest of the breast, or there are several areas of cancer cells in different parts of the breast. A new breast can be created at the time of the mastectomy, and this is known as breast reconstruction. There are several types of reconstruction, including those which involve use of flaps from the tummy and the back to provide shape to the new breast. Augmented reconstruction involves an increase to the original size of the breast, through the use of implants.
Radiotherapy:	Radiotherapy treats cancer by using high-energy rays to destroy the cancer cells. After a lumpectomy, radiotherapy can reduce the risk of cancer arising in the remaining breast tissue; after a mastectomy, radiotherapy to the chest wall may remove any cancer cells left behind. Treatment is usually given in short daily sessions, and a course of radiotherapy may last 3-6 weeks. Side-effects may include reddening of the skin, nausea and tiredness, as well as nerve pain and numbness in the arm.
Staging:	The staging of a cancer describes its size and whether it has spread beyond its original site. There are five stagings (0-4), with stage 4 being the most severe, and indicating secondary cancer which has spread beyond the breast to other parts of the body.

Appendix 1: Glossary of cancer terms (cont.)

Staging (cont.)	<p>The stagings referred to in this research relate to the commonly used medical system, which is as follows:</p> <ul style="list-style-type: none">- Stage 0: when cancer cells are confined to the breast ducts or lobules within the breasts, and have not spread into surrounding breast tissue- Stage 1: the cancer tumour measures less than 2cm; the lymph glands in the armpit are not affected; there are no signs that the cancer has spread elsewhere in the body- Stage 2: the tumour measures between 2-5cm, or the lymph glands are affected, or both; however, there are no signs that the cancer has spread further.
Tamoxifen:	<p>Tamoxifen is one of the most widely used hormonal therapies for breast cancer. It is given after surgery and/or chemotherapy to reduce the chance of cancer coming back; the drug prevents oestrogen in the body from attaching to breast cancer cells and encouraging them to grow. Potential side effects are hot flushes and sweats, weight gain, dryness of the vagina and sleep disturbance. Treatment often involves taking medication for five years.</p>

Appendix 2: Initial interview schedule

Thanks for working through all those details. Do you feel ready to start?
As mentioned before, in this interview we are looking at how a diagnosis of breast cancer can affect a woman's sense of who she is – her identity.
We will start with general questions and then look at some areas in more detail.

1. Can we begin by talking a little about life before breast cancer. How would you have described yourself then?

Back then, if someone who didn't know you had asked "who are you?", what would you have told them?

How do you think other people would have described you then?

Deep inside, how did you think of yourself at that time?

(In pilot, explore whether writing an openly visible, shared list of identities given in answer to questions 1-3 assists with developing answers to Q4-8).

2. Now, can you tell me a little bit about how you see yourself after your experience with cancer ?

If someone asked you to write down a list of things that described you now, what would be on that list?

How do you think other people see you now?

In your own private mind, how do you see yourself now?

3. I'd like to share with you some ways people have thought of themselves (show "Identities: some possible ways of describing who I am", below). Do any of these trigger other identities which are relevant to you, that we haven't already mentioned?

* * * *

4. Let's look at the ways you have described yourself in more detail.

(Go through each identity in turn, starting with pre-cancer identities, then moving to post-cancer identities).

What is involved in being a?

What does the word mean to you?

What things do you value about being a?

What do you find difficult about being a?

How do you feel about being a?

(For pre-post cancer identities) So is being.....now different from the way it was before cancer?(If yes, explore how)

* * * *

Appendix 2: Initial interview schedule (cont.)

5. Do you think that any of the identities, or ways you have described yourself, are connected?

(If yes) What links have you experienced between different identities?

e.g. Friend-stigmatised one; stigmatised one-worker; worker-mother; patient-worker; patient-mother; mother-survivor; worker-survivor; physical being-sexual partner

6. If we look at how you describe yourself now, and how you described yourself before you were diagnosed with cancer, do you see any major differences?

(if yes) What do you think those differences are?

* * * *

7. Can we return to your description of yourself before your cancer diagnosis, which you created at the beginning. Which were the most important identities to you at that point?

Why was beingimportant?

8. Now, let's look at the ways you described yourself after your experience with cancer. Which identities are the most important to you now?

What is important about being ?

9. We've almost come to the end of our interview. Is there anything I have not asked about who you are – your identity – which you feel is important for me to know?

Are there any other parts of yourself – private or public – which you feel we haven't touched on here?

* * * *

10. How have you found taking part today?

Check if participant is showing signs of distress or discomfort. Consider if she looks as she did on arrival, and if not, probe (e.g. you are looking a little concerned/upset – has anything we have talked about left you feeling anxious/upset?).

What did she feel, talking about these experiences?

Talk participant through resources sheet. Confirm that will get back in touch with participant in 6-9 months time, when research findings have been written up, but remind of option to contact me or supervisor in meantime if any issues. Thank participant for taking part.

Identities – Possible Ways of Describing “Who I Am”

1. Social Roles

- Conventional

e.g. woman; mother; step-mother; wife/partner; office worker; lawyer; daughter; sister; colleague/employee/boss; sexual partner; friend.....

- Non Conventional

e.g. alcoholic; drug addict; rebel; anarchist; protester.....

2. Important Activities & Loyalties

e.g. swimmer; cook; dancer; gardener; reader; party-goer; Chelsea supporter.....

3. Organisational Memberships

e.g. anti-apartheid campaigner; church member; political party member.....

4. Cancer-Related Identities

e.g. patient; cancer survivor; victim; person with cancer.....

5. Socio-Demographic Characteristics

e.g. female; white; black; Asian; mixed race.....

6. Social Types of Person/Major Personality Traits

e.g. intellectual; leader; optimist; caring; angry.....

Appendix 3: Revised (final) interview schedule

Thank you for working through all those details. Do you feel ready to start?

As mentioned before, in this interview we are looking at how a diagnosis of breast cancer can affect how a woman sees herself – her identity. I want to understand the world from your point of view, and try as far as I can to understand the meaning of your experience. So while I will be asking questions, it will be you who is helping me understand your experience as closely as I can.

The interview is in four parts. The longest section is the first part, where we will be talking about your sense of who you are now, following your experience of breast cancer. Then we will talk briefly about any connections between aspects of who you are, and those aspects of “you” which are most important to you.

Part 1 – Who Am I?

1. Can we begin by exploring your ideas and feelings about yourself, following your experience of breast cancer.

[give participant “Who Am I?” sheet (below), and talk through instructions.
Estimate c. 5 mins]

2. If you’re ok, what I’d like to do now is to understand a little bit more about the things which you have put down on this sheet, and in what ways they may have been affected by your experience with cancer.

General

Can you tell me more about?/What is involved in being a?

Change

How has being abeen affected – if at all – by your experience with cancer?

Evaluation

What things do you value about being anow.?

What do you find difficult about being anow?

Social

Where do you think your sense of beinghas come from?

How have things outside yourself affected what you feel about being a?

Appendix 3: Revised (final) interview guide (cont.)

3. At this point, I wondered if we could explore whether there are any other aspects of "who you are", which did not come to mind earlier?

[Prompt based on omissions from earlier "Who Am I?" list.]

Roles: (conventional) work; mother; woman; partner; sexual partner; friend.
(non-conventional) rebel; protester; alcoholic.

Activities/Loyalties: interests (e.g. swimming, dancing); campaigner; church member.

Cancer-Related Identities: patient; cancer survivor; victim; person with cancer.

Personality: intellectual; optimist; angry; vulnerable; grateful.

[Explore meaning and any change pre/post cancer as earlier.]

Part 2 Connections

4. One of the things I would like to understand from you was whether it feels like there are connections between different aspects of who you are. Does it feel to you like there are any connections?

[If necessary, prompt with example. E.g. woman – white hair – wisdom.]

5. How are these areas connected?

Part 3 Importance

6. If we look at the ways you described yourself now, which of these have the most significance for you? (significance= mean most, have greatest impact in your sense of who you are).

7. Has what is significant about who you are changed, from before your experience with breast cancer? (yes = in what ways?)

Appendix 3: Revised (final) interview guide (cont.)

Part 4 Other

8. We've almost come to the end of our interview. Is there anything I have not asked about who you are – your identity – which you feel is important for me to know?

Any parts of yourself – public or private – which you feel we haven't touched on here?

Debrief

9. How have you found taking part today?

Check if participant is showing signs of distress or discomfort.
Consider if she looks if she did on arrival, and if not, gently explore (e.g. you are looking a little concerned/upset – has anything we have talked about left you feeling anxious/upset?)

What did you feel, talking about these experiences?

Familiar/unfamiliar thoughts?

Helpful/not helpful?

Do you have any feedback for me about the interview?

Questions make sense? Any parts could have been more clearly explained?

Any questions you feel I should have asked?

Any feedback on ways I handled things that was helpful/not helpful to you?

Talk participant through resources sheet. Ask if happy with current support, and if would find helpful to be put in touch with BCH support.

Confirm that will get back with participant in 6-9 months time, when research findings have been written up.

Remind of option to contact me or supervisor in meantime if any issues.

Thank participant for taking part!

Appendix 3: Revised (final) interview guide (cont.)

Who Am I?

Please write up to 20 simple answers to the question "Who Am I" in the blanks below. Try to answer as if you were giving the answers to yourself, not to someone else.

Please write the answers in the order they occur to you, with a different answer for each blank. Don't worry about logic or 'importance'!

I am _____

I am _____

I am _____

I am _____

I am _____

I am _____

I am _____

I am _____

I am _____

I am _____

I am _____

I am _____

I am _____

I am _____

I am _____

I am _____

I am _____

I am _____

I am _____

Appendix 4: Optional socio-demographic & treatment questionnaire

This research aims to listen to the experiences of younger women with breast cancer. In order to help me explain the characteristics of participants as a group, I would be grateful if you would take a couple of minutes completing the following questionnaire. Your answers will be anonymous and all information will be confidential. Please feel free to leave blank any questions which you do not want to answer.

Age:

Qualifications (please tick any you have obtained):

- | | | | |
|-----------------------------|--------------------------|------------------------|--------------------------|
| None | <input type="checkbox"/> | GCSE/equivalent | <input type="checkbox"/> |
| Trade Apprenticeship | <input type="checkbox"/> | A/AS Levels/equivalent | <input type="checkbox"/> |
| Diploma in Higher Education | <input type="checkbox"/> | First Degree | <input type="checkbox"/> |
| Postgraduate Qualification | <input type="checkbox"/> | Don't Know | <input type="checkbox"/> |

How would you describe your ethnic origin? (Please choose from the following):

- | | | | |
|---------------------------------|--------------------------|-----------------------------|--------------------------|
| Asian - Bangladeshi | <input type="checkbox"/> | Black - African | <input type="checkbox"/> |
| - Indian | <input type="checkbox"/> | - Caribbean | <input type="checkbox"/> |
| - Pakistani | <input type="checkbox"/> | - Other Black background | <input type="checkbox"/> |
| - Other Asian background | <input type="checkbox"/> | Chinese | <input type="checkbox"/> |
| Mixed Ethnic background: | | White | <input type="checkbox"/> |
| - Asian & White | <input type="checkbox"/> | | |
| - Black African & White | <input type="checkbox"/> | Any other ethnic background | <input type="checkbox"/> |
| - Black Caribbean & White | <input type="checkbox"/> | | |
| - Other mixed ethnic background | <input type="checkbox"/> | | |

Appendix 4: Optional socio-demographic & treatment questionnaire (cont.)

Which location best describes where you live?

London area ☐ Leeds area ☐

In which month were you diagnosed with breast cancer?

What staging was given to your breast cancer at diagnosis?

Stage 0/pre-cancer ☐ Stage I ☐ Stage II ☐

What treatment have you received for your breast cancer?(please tick all that apply)

Surgery ☐ Chemotherapy ☐ Radiotherapy ☐

If surgery, what kind of surgery did you experience?(please tick all that apply)

Lumpectomy ☐ Mastectomy ☐ Double mastectomy ☐

Other surgery ☐

If chemotherapy, how many individual sessions of chemotherapy did you experience?

1-2 ☐ 3-4 ☐ 5-6 ☐ 6+ ☐

If radiotherapy, how many weeks of treatment did you experience?

1 or fewer ☐ 3 or fewer ☐ 5 or fewer ☐ 5+ ☐

Thank you for completing this form.

Appendix 5: Breast Cancer Haven authorisation for research



Were you diagnosed with breast cancer between 4 – 18 months ago?

Would you be willing to talk about the way this diagnosis has affected your life?

My name is Catherine Nelson. As part of a doctorate in Counselling Psychology at City University, I am carrying out research into the experiences of women with breast cancer, prompted by my own earlier experience of breast cancer. All my research is confidential and would involve an interview carried out on a one-to-one basis. The research findings will be used to identify ways women may be appropriately supported through their time with cancer.

If you think you might be interested, or would like to find out more, please contact me on 07919 557565 or email me at Catherine.Nelson.1@city.ac.uk. Thank you!

[This research is supervised by Susan van Scoyoc, Chartered Counselling Psychologist (telephone 01245 330003; email susanvanscoyoc@mac.com)].

Appendix 7: Telephone interview with prospective participants

Thank you for calling.

As you saw on the flyer, as part of my doctoral research, I am interested in talking to women to explore how their identity, or sense of who they are, has changed since their diagnosis with breast cancer.

If you choose to take part, you would be helping in two ways:

- you would be helping to increase understanding about the psychological journey faced by people with cancer
- through this understanding, you would be helping those working with people with cancer to develop new programmes of support.

Would it be useful if I talked you through what taking part would involve?
There are 5 things which are important for you to know.

- The first is that research would involve one interview of between 90 minutes and 2 hours. The interview would take place at Breast Cancer Haven. I would ask you some questions and you would have the opportunity to share your experiences about whether your diagnosis with breast cancer has affected your identity, or your sense of who you are. This may include ways in which cancer has negatively or positively changed your sense of self as a person.
- The second thing is that I would like to audio tape the interview, so I can make sure I have an accurate record of our conversation.
- Thirdly, everything which we talk about in our interview will be treated as confidential, and will be guided by professional standards laid down by my professional body, the British Psychological Society. This means that your identity and participation will be known only by me. When the research is written up and sent for publication, no names or identifying details will be included in any document. With your consent, I will delete your identifying details following completion of this research.
- Fourthly, your participation in this study is entirely voluntary. You can withdraw from the study at any time, including in the middle of the interview, should you wish.
- Finally, your participation in this study will also have no impact on your connection to Breast Cancer Haven. Though Breast Cancer Haven has kindly enabled me to talk to potential participants, this research is being run separately through the psychology department at City University. Should you wish to confirm my details there, you can contact either Nikki Hann (Counselling Psychology Programme Administrator: 020 7040 4564; nikki.hann.1@city.ac.uk) or my research supervisor, Susan van Scoyoc (01245 330003; susanvanscoyoc@mac.com).

Do you have any questions on this so far?

**Appendix 7: Telephone interview with prospective participants
(cont.)**

Do you think you might be interested in taking part?

If no: That's fine – I understand thatThank you very much for getting in touch to talk about this. I'm really grateful to you for making the effort to talk through this with me.

If yes: That's great. Thank you. There are a few brief guidelines for this study which I need to check out with you before we arrange to meet. Can I run through these now?

Firstly, when were you diagnosed with breast cancer?

When you were diagnosed, what staging was your cancer?

Was this your first experience of cancer?

Have you had any treatment previously for serious longstanding health issues, such as heart problems, or had any experience of psychological illnesses such as schizophrenia or severe depression?

If don't meet inclusion criteria: I'm really sorry. I'm very grateful for your willingness to participate, but this particular study is focussing only on those (who were diagnosed within P18M/for whom this is the first experience of cancer/whose cancer is Stage 0-2).

I'm sorry that we can't talk further at this stage.

If do meet criteria: Thank you! Can we arrange a time and place to meet? We can try to arrange a time to coincide with your visit to Breast Cancer Haven, if there are rooms available there.

OK, so that'sam/pm.aton

Can I take a contact telephone number in case of problems?

If it's alright with you, I'd also like to send an email or letter so you have the key details of our conversation. Is there an email or a land address which you would be happy for me to use?

OK, that's great.

Thank you very much for agreeing to take part. I look forward to meeting you on

Appendix 8: Pre-interview email/letter (following telephone interview)

Dear

Thank you for agreeing to take part in my research project. As mentioned on the telephone, I wanted to set out the main points we discussed in writing, so you have time to reflect on your involvement before the interview.

What is the research looking at?

My research project seeks to give a voice to women who have been diagnosed with breast cancer. The interview will seek to explore your sense of who you are – your “identity” – both before and after your diagnosis. As part of this discussion, we may review whether parts of your identity have changed, and whether cancer has affected parts of your identity positively or negatively.

Why will this research be useful?

This research can be useful in two ways. It will increase understanding of the mental or psychological “work” involved in dealing with an experience of breast cancer, through communication and/or publication of the research. It will also be used to develop support programmes for those diagnosed with cancer in the future.

What is involved in taking part?

- The research involves one interview of between 90 minutes and 2 hours. I will ask you some questions and you will have the opportunity to share your experiences about any things which have changed in your identity, and any ways in which you have stayed the same, since you were diagnosed with breast cancer.
- The interview will be audio-taped, so I have an accurate record of our conversation.
- Everything we talk about in our interview will be treated as confidential, and will be guided by professional standards laid down by my professional body, the British Psychological Society. This means that your identity and participation will be known only by me. When the research is written up and sent for publication, no names or identifying details will be included in any document. With your consent, I will delete your identifying details following completion of this research.
- Participation in this study is entirely voluntary. You can withdraw from the study at any time, including in the middle of the interview, should you wish.
- It is possible that the areas we cover in the interview may cause you discomfort. However, past research has shown that many people appreciate sharing their experiences with another person, and take pleasure in knowing their experience can be used to benefit others.

Appendix 8: Pre-interview email/letter (following telephone interview) (cont.)

- Your participation in this study will also have no impact on your connection to Breast Cancer Haven. Though Breast Cancer Haven has kindly enabled me to talk to potential participants, this research is being run separately through the psychology department at City University.

Should you wish to confirm my details there, you can contact either Nikki Hann (Counselling Psychology Programme Administrator: 020 7040 4564; nikki.hann.1@city.ac.uk) or my research supervisor, Susan van Scoyoc (01245 330003; susanvanscoyoc@mac.com).

I hope this helps confirm what we talked about on the telephone. If you have any additional questions after reading this, please do not hesitate to contact me.

I am grateful for your agreeing to participate in this research. I look forward to meeting you on atat

With best regards

Yours sincerely

Catherine Nelson
Email: Catherine.Nelson.1@city.ac.uk
Telephone: 07919 557565

Appendix 9: Consent form

This research project is being carried out as part of my doctorate in Counselling Psychology at City University. It is guided by the research principles of the British Psychological Society, and the project is supervised by Susan van Scoyoc, Chartered Counselling Psychologist. I am interested in hearing about your sense of who you are – your identity - both before and after a diagnosis of breast cancer.

Thank you for taking part in this project. We will explore your experiences of identity and cancer in a one-to-one research interview which will take approximately 1 ½ hours. So that I have an accurate record for the research, the interview will be audio-taped. This audio-tape will then be transcribed.

The tape and transcript will only be listened to and read by those directly involved in the research project. Short passages from the interview may be used in the final write-up of the research. However, in all such instances – including tape, transcript and final write up – your confidentiality will be preserved. Names and identifying features will be removed from all relevant items.

There is a possibility that discussion of your experiences might lead to some discomfort or distress. However, many people with cancer have also found it beneficial to share their experiences, particularly if it can be used to help others.

Finally, I would like to emphasise that your participation in this research is voluntary. It is in no way connected to your involvement with Breast Cancer Haven. You are free to refuse to answer any question, and can withdraw at any time.

I agree that the purpose of this research and the nature of my participation in this research have been clearly explained to me in a manner that I understand, and that I have had the opportunity to ask any questions that I might have. I therefore consent to take part in an interview about my experiences of identity following a diagnosis of breast cancer, and consent to this research being audio-taped, transcribed and used for the purpose of research.

Signed:

Printed:

Date:

Appendix 9: Consent form (cont.)

On behalf of those involved in this research, I undertake that confidentiality will be ensured with regard to any material presented from this research. This material will be used for the purposes of research only and the anonymity of this interviewee will be protected.

Signed:
Catherine Nelson

As discussed, I would be happy to share the findings of this research with you, and would welcome your feedback on the findings.

Would you like a report of the results of the project? Yes/No

How would you like to receive this report? Email/Post

Would you be interested in discussing the report? No/Yes – in group/
Yes – only with
researcher

Postal or email address for those asking for a report:

.....
.....
.....

I would be grateful if you would sign both copies of this consent form. One copy will be for you to keep.

Contact Information:

Researcher: Catherine Nelson
 07919 557565
 Catherine.Nelson.1@city.ac.uk

Supervisor: Susan van Scoyoc
 01245 330003
 susanvanscoyoc@mac.com

Appendix 10: Sample transcript

ating how
work these
days?

P: I'm just I'm disgusted with my body now. I hate it. I look in the mirror and I hate it. I don't recognise myself at all. I hate it and I just, and it wouldn't be so bad with the chemo, you know that it was only those months, that was the chemo over, with the radiotherapy that was it, but with the Tamoxifen, it's for five years, it's almost like having to come to terms which I haven't yet that this could be my body for five years! And it's not a nice thought. Sometimes you just think, you know I've even got to the stage where I've gone to friends, they've given me a tablet to keep me alive, but like how I am now if I want to be alive, because I feel like I've lost my life (if Mmm). So yes, I don't like it really at all. And people say, oh you still lovely, but those people aren't inside. I was kind of, no woman really loves their body, we've all got hang ups about different things, but it's like times that by a hundred, and everything you know...

I: What is it you find difficult, most difficult in your body?

P: The weight, the weight gain.

I: The weight gain.

P: Because it's um something I've got no control over. Before I always had control, what I put in my mouth and what exercises I did determined what size I was. I don't have that any more. The fact that the body does its own thing now with all the tablets I've got, but I feel I've got no control. The fact there's like I have no control over my body any more.

Body divorce betw body + sense of self

Repetition of hate; disgust, intensity of response. Disgusted w/ body. Hate it. Don't recognise myself.

Effect of Tamoxifen harder than chemo, process of coming to terms w new body
Signif. of body: state of affairs so critically bound up in life

Paradox: tablet keeping alive, but feel have lost life
Contrast: being alive but hate loss her life
Contrast: other participants own internal feelings
Struggle/disparaten betw outer concerns and inner self exp.
C multiplicity, adaptation w body

Weight gain most diff: no control over body
Prev: cd control w/ this ex/dict

Body does its own thing
(the body' vs I)

Loss of agency

Body has taken over

Appendix 11: Table of super-ordinate themes for Nina

Participant Name: <u>Nina</u>			
Key:	[] = spontaneously stated identities subsumed within higher-level identity	() = creation of identities not spontaneously raised	Italics = picked as most important to participant now
Super-ordinate Theme #1: Challenges to Embodiment			
Identity Area	Content	Text Ref	Key Phrase
Looking and feeling different	1 Difference in physical body	37.25	Mastectomy and a tummy tuck, so physically I am very different
	2 Pleased with breast enlargement	37.28	I did um get my boobs enlarged...as part of it all, so I can't say that I look worse
	3 Mixed feelings about tummy tuck	38.7	I had this bit removed, which is brilliant because I did have quite a big tummy...I do have a scar from there to there, which is enormous, really
	4 Complicated feelings about boob job	38.14	The boobs...they're complicated...the one that I had the mastectomy on...I can't feel it
Body is not my own	1 Breast not being your own	38.18	Although it's physically there, they never really feel like your own any more
	- body property of others	38.23	They belonged more to my doctor than they did to me
	2 Social embarrassment of procedures	39.8	I didn't tell anyone I was having an operation...I think some of it is an embarrassment that people will say, ooh, what have you had done, and I'd have to say, it's a new nipple!
	3 Distress from invasion of privacy of body	39.22	Sometimes I just sort of think, this is my breast!
	- loss of control	39.23	It is really personal, and yet sometimes it's had not to be...people do want to know what's going on
(Tired of having to be tired)	1 Exhaustion from operations reduces activity	21.8	This tiredness means you've got to stop and you've got to um just do a lot less
	2 Exhaustion from taking Tamoxifen	36.10	I did start on Tamoxifen...it really knocked my sleep out. Then I was tired, then I was really tired
	- tiredness made life not worth it	36.13	I don't really care whether this is going to cure me, I don't want it, because without sleep
	3 Being bored	21.10	You can read a book, you can watch TV, there's a lot of monotony
	4 Resenting husband's life	21.11;21.2	I understand my husband needing to go off and have his own life...can't help but feel jealous because I'm not able to do any of that yet
	5 Awareness of temporary identity	22.15	I will one day be able to do my own thing and be a bit happier
	6 C has disrupted her plans	23.29	I had lots of plans for what this year was going to be...and I'm not really making any plans yet
	7 Tiredness cut down previous social life	33.30 34.4	I've got so tired by the evenings that I actually don't want to go out...that's something I miss Having fun sort of disappears, for a bit anyway
Super-ordinate Theme #2: Negotiated Roles			
A. Re-Evaluation of Previous Roles			
Identity Area	Content	Text Ref	Key Phrase
Mother under stress	1 Being a mother is more stressful	2.3	I fight with them and I...shout at them, which I never used to do
	- C has dialled up emotions	2.6	A general thing which has happened with C, which is that I tend to over-react
	2 Extra considerations of C make role harder	2.25	Harder because I've got so many balls in the air
	3 Normal events taking on different value	3.33	In a normal year a really big thing for him and me to have had him going into school. But it was such a small thing!
	4 Managing C information appropriately	4.15	I was keeping them up to date and...trying to keep it simple
	5 If children should be exposed to her physical state after operation	3.6	Something my husband and I talked about a lot, about whether we even thought it was a good idea for them to come in
	6 Managing family in her absence	6.11	...how the family would run without me
	- preserving routine for others	6.30	My husband would have as normal a life as he could, and the kids could go on going to school normally
	7 Sadness being apart from children	7.25	Yeah I mean I missed them hugely
	8 C affecting activities with children	40.23	I don't really want to take my children swimming yet...I have to get undressed in front of them or even go swimming, and I don't like the scarring
	9 Dealing with children quite well	45.7	I'm managing my children pretty well
Intimate then invisible wife	1 Having to manage husband's reaction to C	7.26	Dealing with him was quite um complicated because you know he was quite fraught
	2 Enormity of C made relationship closer at first	16.34	It did bring us together because it's such a big thing to go through and I think it was a bit of a wake-up call for him
	3 Joint activity brought them closer	17.14	There was always bits to talk about...it was really good for us, it did bring us quite close together
	- accompanying on medical visits	17.32	Each time I did um talk to somebody he always made sure he came with me and that made a huge difference
	- working out practical issues	18.28	There was a lot of practicality stuff, and also talking about what the doctors had said...we would talk round it all
	- her decision or theirs?	18.32	I had to decide did I make the decision, or did we make the decision?

Appendix 11: Table of super-ordinate themes for Nina (cont.)

Participant Name: <u>Nina</u>			
Key:	[] = spontaneously stated identities subsumed within higher-level identity	() = creation of identities not spontaneously raised	Italics = picked as most important to participant now
Super-ordinate Theme #2: Negotiated Roles			
A. Re-Evaluation of Previous Roles			
<u>Intimate then invisible wife (cont)</u>	4 Now feeling forgotten by husband 5 Post operative state affects her ability to raise issues 6 Reducing stress on husband	20,23 20,28 20,30 22,30	He's entitled to his own things, but it does consume a lot of his thoughts...I think I feel a bit forgotten sometimes You just feel a bit invisible at the moment I do find it hard to say anything...one of the aspects of...having lots of operations...you get very tired and emotional Her husband went off the rails...and chucked in his job...I'm trying to do the right thing for my husband so he doesn't do that
<u>(Silent friend)</u>	1 Difficult to communicate experience of C 2 Tricky to broach C with newer friends 3 Difficult for her to raise C because upsetting 4 Shocked by support of friends 5 C affecting exchange of friendship 6 Tiredness makes it hard to see friends	24,28 24,33 25,4 25,27 25,32 34,28	You can tell your friends what's happening, but there's an awful lot not happening, it's just being I do find it really difficult to talk to them because they're new friends I don't know if it's got anything to do with the people, I think it's just that...I find it harder to talk about it without getting upset, so in a way I'd rather not I was really shocked at how kind...people People's lives go on, they have their problems, and I think sometimes people find it hard to tell you stuff Sometimes seeing friends...involves having children over...I find having children over quite exhausting, so I don't do as much of that socialising with my children as I did before
<u>(Daughter with special status)</u>	1 Planning how to deal with parents 2 Experiencing special status 3 Feeling abandoned 4 Difficulty of asking for help 5 Colluding to leave C behind	10,16 10,18 10,31 12,12 12,20 13,11	You do have to manage them I felt like I was pregnant again, in how I was treated by my parents ...treating me very kindly, but it was quite...odd They didn't want to call, because they didn't want to catch me when I was tired or upset me, but then again, they didn't call. And that was quite upsetting too, because you sort of felt a bit forgotten I could have called them...it's only a phone call...I'm not that good at asking for help They don't talk too much about it. I think a bit like me they just want it to be gone
<u>(More presentable woman)</u>	1 Larger breasts make her feel more feminine 2 Flatter tummy > feeling more attractive	40,18 40,33	Because I've had a boob job, I do feel more feminine. It does feel really nice to have boobs...that are quite presentable I don't have a tummy any more...and I feel more attractive
<u>(Uncertain about work)</u>	1 Frustration at delay in work plans 2 Physically not ready to cope with work 3 Emotionally not ready to cope with work 4 C unlikely to change job content	46,12 46,20 46,30 47,11	I did think I would be doing something this September...I am a bit disappointed that I am not going to I've still got another operation to go...and I don't want to load it on myself yet. I think I need another year There's quite a lot of juggling, it's not an easy life...you've got to be ready for it...I am aware that I've been quite forgetful and my concentration levels have not been as good I probably would not really change what I was going to do but I don't actually know
<u>(Modified sexuality)</u>	1 Sex correlated with emotional closeness 2 Reduction in arousal post C 3 Overall comfortable with body in sex	48,30 48,25 49,9	For a while our sex life was better, because I think it did bring me and my husband together for a bit, not so recently. And I think my sex life has suffered a bit recently Because I haven't got any sensation in one breast, that makes quite a big difference to um getting aroused Physically...except for the...lack of sensation it's fine
B. Consideration of New Roles			
Identity Area	Content	Text Ref	Key Phrase
<u>Childlike patient</u>	1 Being infantilised	3,22	They slightly spoonfed...they give it to you in bits in a hospital
	2 Placing doctor on pedestal	50,5	You do get very attached to your doctor, they seem to have done amazing things...a certain amount of hero-worship
	3 Loss of control over body	50,9	Your body's not your own thing...public property
<u>(Amazing sense of being a survivor)</u>	1 CS as label for whole experience	50,13	The C survivor thing is...much bigger really in that...you do really feel different for it
	2 Being a witness and help to others	50,23	Stand up and talk about how my experience has been, so that other women are more aware
	3 Pride in surviving C	51,7	There is always an amazing feeling of having survived it
	4 Surviving is both physical and emotional	51,8	It is emotionally and physically a big thing to go through and you have done it

Appendix 11: Table of super-ordinate themes for Nina (cont.)

Participant Name: <u>Nina</u>				
Key:	[] = spontaneously stated identities subsumed within higher-level identity		() = creation of identities not spontaneously raised	Italics = picked as most important to participant now
Super-ordinate Theme #3: Emotional-Existential Identities				
Identity Area	Content	Text Ref	Key Phrase	
<u>Unexpectedly loved</u>	1 Support from husband 2 Overwhelming support from friends 3 Love from C support group - reassurance and understanding from group bolsters new identity	32.30 32.31 33.34	My husband has, if not this week, been amazing I have been quite shocked at just how much people have wanted to help and just try and support me I think my support group too. I feel loved there. They're an important part of my life They're really open about awful things. And that's really great to know that you're not different..the group has given me that feeling that we're all in it together	
<u>Finding a different normal</u> <i>I am different</i> (I am wanting to be normal again) (I am busy)	1 Impact of C on life 2 A different kind of normal 3 Being normal requires addressing C 4 Difference is both physical & psychological 5 Difference is both positive and negative 6 Experience of C isolates from others - importance of support group 7 Development of personal interests 8 Busyness means life is normal - link with tiredness 9 Return to hope	27.23 33.13 9.11 41.30 41.31 9.20 9.17 9.25 34.15 35.21 35.23 45.13	I've always walked away from this thinking this is serious, this is a big life-changer, but it's not going to kill me.. because it was found early..I now think they're gonna be watching me like a hawk It's just having a new identity, having a new um feeling of being normal, but it's just a different normal from how it was before Although I was desperate to be back to normal..I wasn't really able to make any sense of it, or even um talk about it I'm physically different and I'm um I've had C There are good bits, it has made me think about my life. But mainly it's been a long road.. not a different I would wish on anybody You do initially feel like you're the only person in the world who's gone through this Made a huge difference, in just listening to other people and um knowing you're not alone Joining a group and listening to other people..thinking about it is good and important. Much as it's nice to try and blank it, which is sort of the obvious thing to do I have made an effort to do more things for myself than before. I've joined an art group..what I did before was I had friends, went out and was a mum I'm just so desperate to be normal or be doing what I was doing before that I find it quite hard to do less, I just don't want to do less I realise quite regularly that I have exhausted myself It has changed me but I'm getting through it	
<u>Worried about C returning</u>	1 Uncertainty of C returning - worry about C is always there - worry about C returning is private 2 Worry about doing things to prevent C	42.21 44.14 44.22 43.7	Although..I don't think I'll have BC again, and if I do, I probably could have it treated..on the other side, because I've had BC so young ..I have a one in four chance of having it on the other side. And that's quite high that little one, it's always there That's more of a private worry? Yeah, I think because it is difficult. I do find it difficult to talk to people about big things They ..talked about a lot of things you can change: your diet..whether you use perfume. I don't want all that information. I don't want to feel that I've got to change everything, because nobody knows what it is	
<u>Lost dreams</u>	1 Experiencing self as different - strong but also weak 2 Lost dreams - modified ambition - loss of confidence 3 C can feed depression - partly traces to emotional upset - partly links to fear	28.29 28.32 29.4 29.21 29.29 28.20 31.5 31.30	I can't say I'm not gonna do something that I'd always wanted to do, because it isn't that simple, but I just feel very different The thing that's been going around in my head this week has been..the weaker sex. Sometimes we feel like we're the strongest sex, because we've been through so much, we can cope with so much, but actually, I don't think we can cope some of the time I do feel..a bit of a shadow of my former self. It's slightly..a lost dreams kind of thing I just don't think I would be as ambitious with myself and what I want to do next as I probably would have been before I think..it's a bit of confidence It's very easy to get depressed when you've had C. It's you know very normal just to feel you'll never be normal again Some of it is the emotional upset..therefore things get to me quite easily Always your level of anxiety is quite high, and you feel you can't cope with a lot of stuff	
<u>Implications of Research</u>	1 Help of support group in addressing anxiety 2 Prioritising lifestyle changes which can help C 3 Appreciated talking 4 Learnt more about herself, so benefited 5 Acceptance of emotional nature of interview	31.25 43.30 52.1 52.2 52.4	I went to this support group..one of the early things we talked about was..how to manage your anxiety. And it was really really useful I don't know where to begin with it all and again I'm going to blank it..And try not to think about it It's really good to talk, it really is I find things out about myself that I didn't know by talking about them in such detail, so I got quite a lot out of it It was quite emotional, but that's life	

Appendix 12: Table of group super-ordinate themes

1 Challenges to embodiment: The body does its own thing		Page,Line
a. Something alien in my body		
Ursula	It did feel odd at one point that there had been something alien in my body	7,4
Becky	It's a horrendous time [...] like there was a foreign invasion in your body	29,7
Lesley	That to me was like something alien and I just wanted to get it out	4,7
Zoe	Physically I felt contaminated. I felt like I'd got some, well I know it's like poison	37,10
Louise	It was in my mouth, it fell off in my sleep [...] that was part of, your hair is part of your identity	55,8
Nina	Although it's physically there [...] they never really feel like your own any more	38,18
Rachel	I didn't feel [...] my body has done this, it's developed cancer	19,21
b. Just me in a body		
Louise	Now I honestly feel that some days I'm just me in a body and I just get from A to B like a bod	19,33
Zoe	I feel absolutely shattered and worn out and like an old woman sometimes	7,20
Gilly	I'm so tired, exhausted, and I'm not living, I don't feel I'm living, I'm existing	7,15
Becky	Frightened that someone would bang into me or that I would fall [...] dare-devil streak has gone	27,10
Ursula	No real after-effects. My arm goes a bit funny sometimes, but that's normal	6,25
Nina	I did start on Tamoxifen [...] it really knocked my sleep out. Then I was tired, then I was really tired	36,10
c. Coming to terms with how I look		
Louise	I'm disgusted with my body now. I hate it. I look in the mirror and I hate it.	7,2
Lesley	I have accepted who I am and what I look like and this is me, and if you don't like it, well	7,4
Gilly	He's done a fantastic job, the breast surgeon [...] my figure's not an issue to me at all	42,7-20
Becky	Virtually hardly see the scars [...] so the way my body looks it's made no difference at all	27,30
Rachel	Even when the reconstruction's done this one's [...] going to sit down here and this one's going to be [...] round and sit up here	17,19
Nina	Mastectomy and a tummy tuck, so physically I am very different	37,25
Zoe	I don't like the way I look [...] I've got a couple of scars and one boob's a lot smaller than the other	41,7
Ursula	Had so many people see my tits [...] a lot more comfortable with my body	48,5
2 Negotiated roles: What are you looking for now?		Page,Line
a. Partner		
Lesley	We seemed to become a lot closer together [...] if I ever had any doubts [...] they all disappeared	46,18-20
Zoe	I didn't feel like I needed him, for me, you know, but I certainly do now	18,4
Louise	Now it feels like I'm going to be single for ever...just for how I look	14,21-8
Gilly	I paid everything [...] didn't want him to have any sort of control [...] Why do I now feel I want somebody to love me and look after me?	45,14-25
Becky	The first time in my life I really do not want to be in a relationship	30,4
Rachel	It's a more tangible reason why I'm right that I will always be on my own, and now I've got proof in a way	38,6
Nina	It did bring us together because it's such a big thing to go through and I think it was a bit of a wake-up call for him	16,34
Ursula	He always kept his own little diary...so he'd say, don't forget	14,1
b. Mother		
Ursula	Because I haven't got children, it makes a huge difference [...] that must be awful	19,20
Gilly	They give me purpose at the moment, you know, they make, I know they still need me	7,25
Zoe	I still felt guilty because the kids still need you [...] They're innocent, aren't they, they still need their mum	2,29
Lesley	Obviously there was dark times, especially at night [...] But we tried to make it a positive time for the children	41,2-8
Louise	I can't afford to get pregnant, because it could, it would kill me, coz the oestrogen...	64,4
Becky	It's one thing not wanting children, it's another thing being told you can't	45,4
Rachel	Now I'll never have kids at the early stages [...] what is even the point of me going through with all this treatment?	46,5
Nina	My husband would have as normal a life as he could, and the kids could go on going to school normally	6,30
c. Employee/Work colleague		
Rachel	I get five months off full pay [...] I actually got a promotion, a couple of weeks ago	25,9-17
Nina	I've still got another operation to go [...] and I [...] don't want to load it on myself yet. I think I need another year	46,20
Gilly	Before I could cope with it because I had more physical strength but now it's killing me	20,12
Louise	I need to be refreshed on all these things [...] I just feel that I'm not in control any more	25,28
Lesley	It was a way of getting me out without having to pay me any redundancy or anything	20,31
Zoe	I didn't want other people to see me upset. And I didn't feel very good about myself. I felt you know I was a really bad colour	28,18
Becky	The petty...things people worry about, office politics, seems to me absolutely ridiculous	46,2
Ursula	It would be very difficult starting a new job and going [...] can I have Wednesday morning off coz I've gotta go here	13,21

Appendix 12: Table of group super-ordinate themes (cont.)

d. Friend		
Louise	They're the people who have really got me through it and supported me	32,6
Zoe	The friends that are true friends [...] they've supported me, been there for me	29,25
Lesley	They were just there to ...tell me they cared. To make me meals, take me out to eat, to listen to me when I was low	29,25
Gilly	The people you thought were friends you realised weren't friends at all [...] I wouldn't really say any of my friends have been actually there for me	26,6
Becky	People [...] I thought were close..just couldn't deal with talking about it	23,16
Ursula	I don't want to waste time on people I don't like any more...you can out-grow friends	12,14
Rachel	I was just so upset, I told her what...and she just didn't ring to say, how you doing, when's the operation, you know. Nothing	28,17
Nina	You can tell your friends what's happening, but there's an awful lot not happening, it's just being	24,28
e. Survivor		
Louise	I've just survived the battle but I'm still on the journey	59,19
Zoe	I'm not going to be defined as having had breast cancer [...] That's why I wouldn't tell people I'd had cancer	44,21
Nina	It is emotionally and physically a big thing to go through and you have done it	51,8
Rachel	If you're a cancer survivor, it's almost like you're proud that you've had cancer. And it's not that I'm ashamed that I've had cancer [...] it's about wanting it to be done	62,29
Ursula	I've felt a survivor right from the start. They were that confident with me	37,12
Gilly	I don't feel I've survived it. I'm not a survivor at the moment	79,20
Becky	All it means is that you have survived what you've been through so far...it doesn't [...] mean [...] you will never have it again	51,17
Lesley	I'm on the Tamoxifen, which is supposed to keep it at bay [...] but whether I'll be mentally free from cancer, I don't know	51,5
3 Emotional-existential dilemmas: Re-learning what life's all about		Page,Line
a. Facing my own mortality		
Becky	You go from being apparently healthy one minute to being dead the next	48,2
Gilly	It's made me realise my mortality...the way I've been living my life...has eventually caught up with me	3,25
Rachel	People have said to me, you're the healthiest person I know...so that's just made me think, is that just a load of rubbish?	21,20
Zoe	The only thing we're sure of in our life, that one day we're going to die [...] you don't want to die when you're forty or thirty-nine	9,3
Louise	She [Jade Goody] was the flipside of the coin. This is like me fighting it to survive but this is what can happen	38,5
Nina	Although...I don't think I'll have breast cancer again [...] on the other side, because I've had breast cancer so young...I have a one in four chance of having it on the other side. And that's quite high	42,21
Ursula	This potentially dreadful thing's happened, but [...] it's happened in a way that's not going to kill me	3,2
Lesley	My body obviously fights these things. you know me mother says I'm a cat with nine lives	5,27
b. Assessing autonomy: Strength and vulnerability		
i. Strength		
Ursula	In a morbid kind of way, a bit special, because [...] I'm one of a small group of people that have had breast cancer and survived	48,33
Louise	I am brave as in I don't let the side down, telling them all	44,22
Rachel	It's this terrible thing, it's kind of like a sense that I've...I'm strong because I...don't really need any help...and it's in such a contrast of this feeling of being alone and wanting to be around people	50,28
Becky	I don't want to be around negative people any more [...] more able to say that now...if they don't like it, tough	12,2-8
Gilly	Against all the odds, losing lots of money through relationships...no support, I've brought up two beautiful children and kept my head above water	34,11-16
Nina	Really great to know...that you're not different...the group has given me that feeling that we're all in it together	33,11
Lesley	Not as strong as some others lifting things [...] if I wasn't strong after having all these experiences I have had, I wouldn't be here	3,4
ii. Vulnerability		
Louise	I feel cheated that I've lost the best years of my life because of it	42,8
Rachel	It actually just compounds...the other reasons why I'm unhappy [...] it adds to that [...] which is about being alone	36,26
Becky	Really hard for me to sit and think about [...] dreadful fear...that if it comes back it's not gonna be so simple	43,26
Gilly	I'm a bit like Samson...I've had my hair cut off. I was much stronger before cancer	37,2
Zoe	I put that act on, but when it's just night time, or when I'm on me own...I can't hide from that, it's there in me mind	14,29
Nina	Always your level of anxiety is quite high, and you feel you can't cope with a lot of stuff	31,30
Lesley	It don't take the fear away because you're always fearful [...] it just gives you a greater understanding	55,26

Appendix 12: Table of group super-ordinate themes (cont.)

3 Emotional-existential dilemmas: Re-learning what life's all about (cont.)		Page,Line
c. Following a different path to before		
Gilly	I am a mother, I am a very hardworking person, I am a teacher, I'm all those things, but I don't know who I am any more	5,22
Louise	I'll always appreciate it because I'll know what the flipside is	53,32
Zoe	I try and make the most of each day..but [...] it's still there and that's the reason why I'm doing it	22,4
Lesley	Because I've come through..and I have got this strength, that I have to be there now for others	10,5
Becky	Instead of beating myself and other people up, I now embrace [...] life..and that's the key difference	52,17
Rachel	People say you know they evaluate their life [...] whereas actually I feel I don't have a lot of things left that I wanted to do and haven't done	43,13
Nina	I do feel..a bit of a shadow of my former self. It's slightly..a lost dreams kind of thing	29,4

Appendix 13: Table of frequency of occurrence of super-ordinate themes across participants

	Louise	Zoe	Lesley	Becky	Ursula	Gilly	Nina	Rachel
1 Challenges to Embodiment								
a. Something Alien in my Body	X	X	X	X	X		X	
b. Just Me in a Body	X	X		X	X	X	X	
c. Coming to Terms With How I Look	X		X	X		X	X	X
2 Negotiated Roles								
Re-Evaluated Roles								
a. Partner	X	X	X	X	(X)	X	X	X
b. Mother	X	X	X	X	(X)	X	X	X
c. Work	X	X	X	X	X	X	X	X
d. Friend	X	X	X	X	X	X	X	X
e. Woman	X	X		X	X		X	X
f. Daughter	X	X		X	X	X	(X)	X
g. Sister/Brother	X					X		X
h. Sexual Being	X	X	X	X	X	X	X	X
Consideration of New Roles								
a. Patient	X	X			X	X	X	X
b. Survivor	X	X	X	X	X	X	X	X
3 Emotional-Existential Dilemmas								
a. Facing My Own Mortality	X	X	X	X	X	X		X
b. Assessing Autonomy	X	X	X	X	X	X	X	X
c. Following a Different Path to Before	X	X	X	X	X	X	X	X
Key:	X	Present		(X)	Only barely mentioned			
	X	Regarded as salient identity area by participant						