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# The Phenomenon of Coping for Women with Primary Breast Cancer

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# **Statement of Authorship**

This dissertation was written by Karen Dyer and has ethical approval from the New School of Psychotherapy and Counselling and the Psychology Department of Middlesex University. It is submitted in partial fulfilment of the requirements of the New School of Psychotherapy and Counselling and the Psychology Department of Middlesex University for the Degree of Doctor of Counselling Psychology and Existential Psychotherapy. The author reports no conflicts of interest and is solely responsible for the content and writing of the dissertation.

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#### **Abstract**

This study provides insight into the phenomenon of coping, revealing detailed information outlining what the participants coped with and how they managed life, both during and after a diagnosis of primary breast cancer. This experience was reported as a significant life event for all participants, requiring flexible use of different coping styles to adjust to the global disruption in their lives. The interview questions for the study used the existential framework of The Four Dimensions (van Deurzen, 2010; van Deurzen & Arnold-Baker, 2005). This framework guided the extraction of detailed accounts relating to the phenomenon of coping across the physical, personal, social, and spiritual dimensions of lived experience. In addition, participants also shared their experience of time. IPA methodology (Smith et al., 2009) was used to interpret the data, producing findings describing coping across the dimensions of lived existence and time informed by an existential lens, highlighting the use of meaning-focused coping strategies particularly in the social and spiritual dimensions of lived experience. The findings are important because they have significant implications for the psychological support of women with primary breast cancer and point to individual differences in coping repertoires and resources. The researcher recommends how an existential-phenomenological approach could be used with this population. Recommendations for further research include studies that consider coping for women with metastatic breast cancer, studies that specifically explore difficulties in coping with anxiety at the end of breast cancer treatment, studies that explore coping specifically with iatrogenic trauma after breast cancer surgery, and studies that consider coping with long-term burdens of breast cancer, particularly health inequalities for women with fewer socioeconomic advantages.

Key words: coping, existential, phenomenological, primary breast cancer, resilience, benefit finding, meaning-focused coping, existential coping

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#### **Chapter 1 Introduction**

The power of coping in the face of adversity, such as a cancer diagnosis, intrigues me. I have been inspired by the courage and strength of character that I have witnessed in people with whom I have had the privilege to work in hospice, hospital, and community cancer care settings. I am particularly interested in how women cope with living with breast cancer. The general research question for this study is: "What is the lived experience of coping when faced with a diagnosis of primary breast cancer?" Specific questions are:

- i) What is the experience of coping in the physical, personal, social, and spiritual dimensions of life?
- ii) What existential givens and concerns did participants face?
- iii) How did they cope with existential givens and concerns?
- iv) Is coping experienced differently in each dimension of lived experience?
- v) How did the experience of time intersect with how the participants coped?

I hope that these questions focused on the lived experience of coping will provide rich data for analysis, extend the understanding of what women with primary breast cancer cope with, and learn more about how they managed during their cancer journeys.

As a woman I am acutely aware of the high incidence of breast cancer diagnosis. The statistics currently reported by Cancer Research UK (Cancer Research, UK, n.d.) estimates that 1 in 8 women will receive a diagnosis over the course of a lifetime and breast cancer accounts for 15% of all cancers reported. Despite the high incidence of breast cancer, the good news is that over the past 40 years breast cancer survival rates have doubled from 40% to 78% meaning that mortality rates have decreased by 35%. An estimated 600,000 people in the UK are living after breast cancer and this number is expected to rise to 1.2 million by 2030 (Breast Cancer Now., n.d.). Given these statistics it is important to consider the experiences of living with the impact of breast cancer because facing cancer and an uncertain future is not an easy psychological space to occupy.

Exploring the lived experience of coping for women after breast cancer could potentially lead to new knowledge about how women cope, both during and after illness. The study will look at what it is to adapt and accept, or reject life changes, that arise when diagnosed with breast cancer across all dimensions of lived experience; the physical, personal, social and spiritual (van Deurzen & Arnold-Baker, 2005). This research is personally and professionally meaningful to me. I have had my own experiences being recalled after mammography, and several of my friends have survived breast cancer. Professionally in my former work as a Registered Nurse, then as an Art Therapist and more recently in the role of Trainee Counselling Psychologist working with cancer patients in an NHS placement. Some of these inspiring women eventually lost the battle with this awful disease, yet they remained emotionally strong to the end of life. It is their courage and strength that have motivated me to research coping, to try to know more about this phenomenon that makes humans able to tolerate difficult life changing illness while still finding meaning and the will to fight on.

#### 1.1 Aims of the research

The aims of this research project are to explore the lived experience of coping to better understand the phenomenon of coping in women who have survived a primary breast cancer diagnosis and medical treatments. I hope to give women co-researchers a voice to be able to shed light on how coping with cancer is experienced. By understanding more about coping, what it is like to adjust and change, how and when the need for coping manifests and if it is considered important on a personal level when faced with a limit situation such as a cancer diagnosis. My hope is that this research will help both clients and their therapists recognize the importance of the meanings attached to coping and coping strategies, and in turn be more able to cope and foster wellbeing.

#### 1.2 Resources the Researcher Brings to the Project

When I was eighteen years old, I left my island home and went on an adventure to live in London and study nursing at The Middlesex Hospital, sadly now changed into a block of luxury flats

in the West End of the city. My first ward assignment was an oncology unit and within the first week my job was to sit and hold the hand of a woman, a nun who was dying. I can remember the smell of her body, the thinness of her frail white skin and her shallow breathing. She smiled at me briefly then closed her eyes as I took hold of her hand. I just sat there, as I had been instructed to do so by the Ward Sister, being afraid to move just in case she died when I was not looking. It sounds strange to me now, but at eighteen I had never seen a person die, nor really expected that to be on the agenda, after all, hospitals cure people and I had not seen too many people dying like this on my favorite TV soap opera 'General Hospital'. The part that struck me the most was the quiet exit, how the life force just ebbed away as her breathing stopped. The next death I witnessed was not calm and peaceful; it was the antithesis of my lady nun. He was a huge man who had a raging fever and gurgled and gasped and finally had a massive seizure that resulted in a respiratory arrest and death. My induction into end-of-life realities was swift and I discovered that I possessed an ability to face into and tolerate witnessing pain and distress in others and myself as a part of life. At first, I thought all nurses managed this well, but over the years I came to the realization that this is not always true. Some nurses choose to work in areas where death rarely visits. My journey has meandered along a path that has often looped back, affording me experiences in companioning the dying; first as a Registered Nurse working with seriously ill patients, later as a nurse advocate for the care of persons living and dying of AIDS, and later as an art therapist and bereavement counsellor in hospice and community cancer care settings. During my counselling psychology training more than three hundred of my clinical placement hours were gained working within a psycho-oncology support team in an NHS setting. I value my work experiences and believe that companioning people as they face into life limiting issues is important. I detest the idea of people being excluded, and living and dying in distress, a sad reality in my lived experience of the 1980's AIDS crisis.

I have nursed and shared psychotherapeutic relationships with many women diagnosed with breast cancer. I have also witnessed the disease manifest in close friends and colleagues. It is a

disease that impacts the entire person, not just a physical onslaught but an emotional, social, and spiritual challenge as well.

Although I have not directly experienced breast cancer, I have had breast health issues. I have had multiple mammograms, experienced the dreaded recall letter and undergone guided needle biopsy under ultrasound. Reflecting on my own experience, what distressed me most was not feeling heard by the doctors and having to insist upon investigations, which resulted in a surgical procedure. Nurses are notoriously known for hypochondria, but my experience made me wonder about women who do not share my tenacity and who might accept the word of a doctor as expert and end up being misdiagnosed or diagnosed at a later stage where treatment would not be curative. Sadly, I have had first-hand experience working with women with a similar narrative who are now dead.

I am passionate about this research topic because I believe it could add to the literature on the psychological implications of breast cancer, giving women a voice to share their experience, and shed more light on the nature of coping and resilience. Although I have my own personal experience of a breast cancer scare, and many years of work-life experience working with a cancer population, I am certain that using my skills as a trainee counselling psychologist will help me to remain reflexive and aware as I try to bracket previous knowledge and my personal biases. For example, I know that when I hear narratives of negative medical experiences, I must take care not to collude with the client's interpretation or perception based on my own experiences and those told to me by others. I also must check myself when clients tell me that they do not want to proceed with tried and tested medical treatments but instead want to try natural remedies first. As a former nurse the ingrained medical training is hard to forget. I have witnessed cases of women who have gone the natural, choosing to refuse evidenced based surgery, chemotherapy and radiation. These women usually present again within the year with advanced disease with options only for palliative treatment to manage symptoms. The symptoms in the case of advanced breast cancer can include bone metastases causing intractable pain in the spine and large bones of the hips and legs, devastating

fungating masses that eat into the chest wall and widespread organ metastases, often in the brain, lungs, and liver. During my clinical placement within a psycho-oncology support team as a trainee counselling psychologist I have held the space for clients as they grapple with making informed decisions about their care. It is a delicate balance to explore their understanding about the information and options they face into in a holding way without scaring clients into agreeing to medical treatments. I have learned that I need to remain open and accept the choices clients make for themselves, and how to stay alongside them without judging their choices. Using an existential-phenomenological approach is helpful because it values remaining curious and open to whatever arises in a therapeutic setting. I believe that these skills will readily transfer and will help me conduct my research interviews, using the methodology of Interpretive Phenomenological Analysis (Smith et al., 2009).

#### 1.3 Conceptualisation of Coping

This study views coping as an essential and valuable construct for self-regulation, health, and well-being (Frydenberg, 2014). Coping is also important to help people survive complex life challenges such as cancer, with the potential to thrive as they find new meaning in their experiences (Snyder, 1999; van Deurzen, 2021). Theoretically, coping strategies and styles are neither good nor bad; they are simply ways to evaluate context-sensitive responses. For example, using drugs or alcohol might be a way to manage emotional pain. However, many health professionals and psychologists would argue that this could represent a maladaptive or unhealthy coping method. Evaluating how a person is coping with life is a vital element of clinical practice; when people reflect on how they are coping with any given situation, they can consider alternate options and choices.

Coping was first defined by Lazarus and Folkman as the "constantly changing cognitive and behavioural efforts necessary to manage, master, reduce or tolerate a troubled person-environment relationship" (Lazarus, R. S. & Folkman, 1984). Later this definition evolved to the "cognitive and behavioural efforts to manage specific external or internal demands (and conflicts between them)

that are appraised as taxing or exceeding the resources of a person" (Lazarus, Richard S., 1991, p.112). These two definitions appear to underpin most coping theories that have evolved over the past forty years (Frydenberg, 2014; Frydenberg, 2017; Schwarzer & Schwarzer, 1996). Psychology researchers and scholars continue to build upon these foundational ideas, extending our understanding of coping beyond its cognitive-behavioural roots to embrace the influences of culture, context and meaning.

Some coping theories prefer to limit the concept of coping to voluntary responses (Lazarus & Folkman, 1984), while others include involuntary and automatic responses (Compas et al., 2001a). Other coping theorists, such as Hobfoll, position coping as people's efforts as they strive to get, keep, and protect resources. Conservation of Resources Theory (COR) views resources as things, relationships, and situations that people value and posit that stress arises when resources are threatened or lost (Hobfoll, 1989; Hobfoll, 2011). Leventhal's Self-Regulatory Model of Illness Behavior (SRM) provides a framework to understand how symptoms and emotional responses during a health threat can influence perception of illness and guide coping behavior (Leventhal et al., 1997). SRM is based on approaches to problem solving and suggests illness can be dealt with the same way as other problems; first by interpretation or making sense of the problem, then by coping, or dealing with the problem to regain a state of equilibrium, and thirdly appraisal, to assess if the coping strategy was successful or not. Crisis Theory (Moos & Billings, 1982; Moos & Schaefer, 1989) offers a conceptual framework to understand how people cope with the crisis of illness; "through cognitive appraisal of its significance, the crisis sets forth basic adaptive tasks to which varied coping skills can be applied" (Moos, Rudolf, H. & Schaefer, 1989 p.9). The Theory of Cognitive Adaptation (Taylor, S. E. et al., 1984b) holds that adjustment after breast cancer relies on the ability of people to self-regulate to maintain the status quo using three processes; a search for meaning, a search for mastery and a process of self-enhancement; positing that all are needed to cultivate and maintain illusions that can lead to a process of cognitive adaptation.

Coping is a broad concept with little agreement on its structure. The literature reveals over one hundred different categorisation schemes and many systems for measuring coping (Skinner et al., 2003). Two of the most common coping descriptors are problem-focused versus emotion-focused coping (Lazarus & Folkman, 1984) and engagement (or approach) versus disengagement (or avoidant) coping (Carver & Connor-Smith, 2010; Compas et al., 2001). Skinner et al. (2003) suggest that coping cannot be limited to one universal model because coping is not a specific observable behaviour. Instead, they believe that coping is better understood as an organisational construct describing various actions to manage life events. After reviewing and analysing one hundred coping assessments they produced a list of 400 coping strategies. They concluded that coping strategies differed from coping styles and devised a list of thirteen core coping styles: Problem-solving, Support seeking, Avoidance, Distraction, Cognitive restructuring, Rumination, Helplessness, Social withdrawal, Emotional regulation, Information seeking, Negotiation, Opposition and Delegation.
They recommended that their system replace other coping systems such as problem-focused versus emotion-focused coping, or engagement (or approach) versus disengagement (or avoidant) coping models.

After reviewing the literature, the researcher identified a gap in the conceptualization of coping from an existential theoretical perspective. The term existential coping is limited to dealing with spiritual concerns (Ahmadi, 2006; Ahmadi & Ahmadi, 2015; Ahmadi et al., 2017). This study hopes to bridge this gap in the coping literature by exploring the existential nature of the phenomenon of coping for a group of women who coped with the threat of primary breast cancer at a particular point in time, bound within the cultural norms of the UK.

#### 1.4 Structure of the Project

It soon became apparent while reviewing the literature on coping that it has been one of the most highly researched fields in psychology over the past fifty years. A Google Scholar search for 'peer-reviewed literature on coping' yielded 113,000 results. While a literature search of the

EBSCOhost Research Databases and APA PsychInfo returned 80,839 items with the Boolean phrase 'coping or coping strategies or coping skills or coping behaviour or cope'. Another important finding in the psychology literature is that coping, and resilience are well-known interrelated concepts. For example, Van der Hallen et al. (2020 p.479) observe how the terms coping and resilience "have often been equated with each other – to the point where some seem to use them interchangeably". Frydenberg agrees, offering her opinion that the coping literature appears to have been overshadowed by resilience studies in the past twenty years (2017) This observation underpinned my decision to review the broader literature to include studies that researched coping with breast cancer and those that explored both coping and resilience in the context of breast cancer to find potential gaps in the literature that this study could address.

Chapter three covers methodology, outlining my decision to utilize Interpretative

Phenomenological Analysis as my research method using an existentially informed framework of the four worlds and time. This study section includes a detailed account of the method, sample recruitment, ethical considerations, and data analysis.

The study findings across the participant interviews are explained in chapter four, organizing the results using the four dimensions and time framework. The researcher separated the findings to explicitly show what the participants coped with and how each coped with their experiences of primary breast cancer using various coping strategies and styles.

The final chapter discusses the key findings, critically evaluating them in relation to the broader coping literature and the research questions. The research-to-practice implications of findings are discussed, offering recommendations for psychology and psychotherapy practice.

Reflexivity on the dilemmas of the knowledge journey and research process are discussed alongside an evaluation of the strengths and limits of the research to support the study's validity. The study concludes with a summary of the key offerings of the research project, answering the research question 'What is the lived experience of coping when faced with a diagnosis of primary breast cancer?', positioning it within the wider literature along with recommendations for future research.

#### **Chapter 2 Literature Review**

This literature review will briefly cover the key areas of inquiry and theoretical perspectives to get an overview of the existing body of research on coping and resilience. Resilience is a subject that has been studied extensively over the past 20 years across diverse fields, including but not limited to; education (Challen et al., 2014; Hatzichristou et al., 2014), nursing (Rogers-Clark, 2002; Sherman et al., 2012; Soo & Sherman, 2015; Szanton & Gill, 2010), psychology (Flach, 1990; Flach, 1997; Southwick et al., 2014; Windle et al., 2011), and sociology (Ungar, 2003). Windle et al. (2011 p.1) suggest that the interest in resilience increased in response to "dissatisfaction with 'deficit' models of illness and psychopathology", and that resilience continues to be of interest to health professionals and policy makers due to the potential impact of resilience on health, wellbeing and quality of life. Generous funding for resilience research has been provided by the Medical Research Council and the Economic and Social Research Council in the UK, recognizing that resilience as an important component in health across the lifespan. Similar funding initiatives calling for more research on resilience in the United States are evidenced by the National Institutes of Health, Division of Extramural Research of the National Center for Complementary and Integrative Health (NCCIH & NIH, 2016) call for research proposals. Grant funding was made available to address identified gaps in the resilience literature including predisposing factors, classes of adverse exposures, dynamic processes of adaptation and environmental moderators. Research was requested to be conducted using a framework with the following four features: assessment of a baseline prior to challenge, characterization of a specific challenge (acute or chronic), post-challenge measures of outcomes that characterize the response over time, including responses across multiple domains (e.g., physiological, psychological) and predictors of outcomes, including predisposing factors at the individual and environmental levels (NCCIH & NIH, 2016). I think that these parameters pose a challenge to the research community; for example, I am finding it difficult to imagine how to assess a baseline prior to a challenge such as a breast cancer diagnosis, other than a self-report of

historical wellness; since the facticity of a cancer diagnosis may imply that an individual has already been exposed to a trauma/stressor. For me this call for research confirms that there is still much to learn about resilience. Resilience is a broad topic and to best link existing research knowledge with my question: "What is the lived experience of coping when faced with a diagnosis and treatment for breast cancer?" I have had to narrow the focus to explore the process of coping and adapting as the prerequisites for an outcome of resilience. My literature review process involved two phases. The first was a review of research on resilience and the second research that looked at both coping and resilience.

## 2.1 Introduction to the Literature on Resilience

Using EBSCOhost search engine (via Middlesex University online portal) searches for literature on the topic of resilience returned vast amounts of data ranging from resilience in human studies to resilience in science, agriculture and engineering. Narrowing the search for more specific literature was achieved using Boolean phrase 'Resilience AND Breast AND Cancer'. The search included the following databases: AMED, eBook Collection (EBSCOhost), MEDLINE, PsycARTICLES, PsycINFO and PsycTESTS. Limiters included the date range 1970 to 2018 with. This narrowed search returned 174 documents. In a subsequent search I used the Boolean phrase 'coping and breast and cancer and phenomenology' returned only 14 results. A Google Scholar search using 'experience of coping and IPA method and breast and cancer and women' returned 917 results. Many studies looked at coping with something specific about breast cancer using qualitative methods, but none considered the experience of coping with primary breast cancer and lived experience through an existential lens.

In a meta-analysis of resilience definitions and study methods (Johnston et al., 2015), offer their observations regarding the lack of consensus in research concerning the definition of resilience and the limited number of published research papers addressing how resilience is measured and conceptualized. They conclude that resilience is not a fixed personality trait but rather a dynamic

process that varies across the lifespan, and that resilience is mediated by context and psychological perception of external events. This view agrees with the definition of resilience selected for this this enquiry, defining resilience as the psychological ability to regain or maintain mental health in the face of adversity including physical illness (Stewart & Yuen, 2011). In this study the adversity under scrutiny is breast cancer, and the research question is: 'What is the lived experience of coping when facing breast cancer?' Resilience is not an easy concept to measure or study due to its paradoxical nature and disagreements in how it has been conceptualized in the literature. The paradox of resilience is the necessity of embracing change as a requisite to persist. From an evolutionary perspective those who do not adapt to a changing environment die out. This can be seen in the natural world evidenced with species on the endangered list at risk of extinction influenced by environmental changes such as global warming or encroachment on habitat by humans. Another example can be seen in business models where technology advances have huge impacts on employment and sales such as in the photographic industry. The move from film to digital was a massive shift that had far reaching impact. Businesses that adapted and found new ways of coping with technological advances thrived and those who did not adapt ceased to exist. Given that business is driven by human decision-making it is easy to assume that the ability to shift and change, in essence to have coping flexibility and thus be resilient, is an innate human given. Yet not everyone is resilient, or at least people are not necessarily resilient all the time. Hence the debate continues regarding resilience as a stable personality trait. Flach (1990; 1997) suggests in his theory of resilient personalities that resilient attributes include both inner strengths and interpersonal strengths; his writing positions resilience as a psychobiological construct. This approach is congruent with the Society-to-Cells framework offered by nursing research that views resilient potential as an innate part of being human, albeit one that is not a fixed trait but instead a "process and capacity" (Szanton & Gill, 2010, p.332).

#### 2.2 Introduction to the Coping Literature

Coping research in psychology appears to have been eclipsed by the popularity of research on resilience (Frydenberg, 2017). However, the link between coping and accommodating or adapting to change, that is coping flexibility, has been the focus of much quantitative research and the creation of coping measurement scales. Frydenberg (2017, p.31) offers her view that coping theories such as transactional theory (Lazarus & Folkman, 1984) (Lazarus & Folkman, 1984) and conservation of resources theory (Hobfoll, 1989) are helpful to underpin a framework to understand how people cope with stress and traumatic life events, such as a cancer diagnosis, and how coping is the process resulting in an outcome of resilience.

Originally proposed in the 1960s (Lazarus, Richard S., 1966) the transactional model of coping has continued to be developed over the past six decades, confirming that its basic tenants about how humans cope has stood the test of time (Folkman et al., 1986; Lazarus, Richard S., 1998) and scholars have continued to expand upon his earlier works, validating these concepts to explore the process of coping (Biggs et al., 2017). The important contribution of Folkman and Moskowitz (Folkman et al., 1986) expanded the coping resources inherent in the physical, psychological, and social dimensions of life outlined in the original stress-appraisal theory (Lazarus & Folkman, 1984) to include studies on positive affect and meaning-focused coping (Folkman & Moskowitz, 2000; Folkman & Moskowitz, 2007; Park, C. L. & Folkman, 1997) . This was an essential addition because positive affect has been linked to positive health outcomes (Fredrickson & Losada, 2005) and underpins the "Broaden and Build Model of Positive Emotions" (Fredrickson, 1998), evidencing how physical, emotional, and social resources increase when people engage in positive emotions such as joy, interest, pride, or love. Positive emotions also play a role in neutralising negative emotions (Fredrickson & Levenson, 1998). Meaning-focused coping strategies include the following concepts: realigning priorities, adaptive goal processes, benefit finding, benefit reminding, and infusing ordinary events with meaning (Folkman & Moskowitz, 2007).

# 2.3 Scope of Existing Research on Coping and Resilience in Women with Breast Cancer

Studies about coping and resilience in women with a diagnosis of breast cancer cover a broad range of topics and sample sets. The majority of the retrieved research meeting my search criteria is quantitative, with many utilizing questionnaires such as the Connor Davidson Resilience Scale (Connor & Davidson, 2003), Quality of Life assessment scales (Ware, J. E. JE et al., 1993; Ware, JE et al., 2000), Impact of Events scale (Horowitz et al., 1979) and Perceived Stress Scale (Cohen et al., 1983) to measure stress related to a cancer diagnosis in attempts to correlate the role of resilience and positive coping styles in response to the impact of illness.

The role of resilience and coping in women with breast cancer has also been the focus of multicultural reviews since the disease impacts and affects women globally. Multicultural research points to similarities and differences on how resilience is framed in various cultural and ethnic contexts including studies on African American (Kennedy & Rollins, 2016), Chinese (Hsiao et al., 2016; Huang et al., 2017; Kennedy & Rollins, 2016; Wu et al., 2018), Greek (Fradelos et al., 2017), Italian (Di Giacomo et al., 2016), and Polish (Izydorczyk et al., 2018).

Coping and resilience have also been studied in relation to quality of life and social support (Dubey et al., 2015; Eicher et al., 2015; Mallinckrodt et al., 2012; Zhang et al., 2017). Findings show that social support appears to play an important role in how people cope and manage to be resilient. Two research papers explored quality of life and social support in minority women with breast cancer addressing how lesbian, gay or bisexual women's experience may differ due to their potential psychosocial position as marginalized members of society (Boehmer et al., 2013; Kamen et al., 2017).

The relationship between resilience and emotional distress (depression and anxiety) in women coping with breast cancer is another area of research (Di Giacomo et al., 2016; Fradelos et al., 2017; Markovitz et al., 2015; Ristevska-Dimitrovska et al., 2015), with the findings suggesting a positive correlation between higher levels of resilience and emotional wellbeing and a negative

correlation between depression and resilience in that higher levels of depression are linked with lower levels of resilience.

A 2016 public health qualitative study using the phenomenological method of Max van Manen (2002), reported how participants who experienced the loss of hair related to chemotherapy treatment viewed this as a stressful event that negatively affected their self-esteem and ability to cope (Williams, F. & Jeanetta, 2016). Two nursing studies using qualitative methodologies, also reported how breast cancer treatment impacted upon lived experience and held implications for coping (Drageset et al., 2015; Tighe et al., 2011).

#### 2.4 Theoretical Perspectives

Snyder (1999) provides an account of coping as a psychological construct with psychodynamic roots, set in the theories of defense mechanisms. In a synthesis of Freudian and Adlerian theory, Snyder (1999) credits the contribution of Anna Freud (Freud, 2018, 1936), who expanded defense mechanism theories to include both internal and external responses to threats. Anna Freud's lasting contribution was that people do not use all defense mechanisms but instead have favored ones and this is compared to current coping theory that suggests people select certain strategies from coping repertoires (Snyder, 1999).

Psychoanalytic theorists position resilience as a personality construct, describing egoresiliency as "a capacity that enables individuals to adapt to constantly changing environmental demands" (Farkas & Orosz, 2015). Jack Block is credited with conceptualizing psychological resiliency in the 1950s, with his theory of personality as an affect processing system in which ego-resiliency is coupled with ego-control. Viewed as a continuum with ego-resiliency at one end of the spectrum and ego-brittle at the opposing end the theory suggests that persons who are ego-brittle will be more likely to struggle with attachment related anxiety and rumination compared with ego-resiliency which is associated with a flexible problem-solving style. This psychoanalytic viewpoint agrees with coping with breast cancer literature that sees people who can be flexible in their ways of

coping with changes in their environment as more resilient to depression and anxiety (Di Giacomo et al., 2016; Fradelos et al., 2017; Markovitz et al., 2015; Ristevska-Dimitrovska et al., 2015).

Cognitive Behavioural Theory (CBT) underpins resilience training initiatives such as *Stress Management and Resilience Training (SMART)* (Loprinzi et al., 2011), *Be Resilient to Breast Cancer* (Ye et al., 2016), Mindfulness support groups (Hsiao et al., 2016) and a Norwegian group program for breast cancer survivors that integrates 'evidence-based resilience factors' into its manual covering 16 group sessions (Friborg et al., 2005). In a 2017 study exploring the relationship between locus of control and hope among survivors of intimate partner violence, findings suggest a positive relationship between internal and powerful others locus of control are both associated with hope (Munoz et al., 2017). These results could transfer to a cancer population in that having a sense of control or choice over treatment regimens and having a supportive social network may be linked to hope for survival.

Positive psychology frames resilience as one of many beneficial health outcomes of positive emotions and strength acknowledgement in human beings, with research focusing on the efficacy of group interventions (Cerezo et al., 2014). Other studies have looked at the role of gratitude (Algoe & Stanton, 2012) and positive affect (Zautra et al., 2005) as factors of resilience. Post-traumatic growth (PTG) researchers (Gallagher-Ross, 2012; Pat-Horenczyk et al., 2015; Ruini et al., 2013) have identified personal and contextual personal resources or strengths that are linked to resilience in women with breast cancer. Of interest it is the inoculation and/or vaccination effect of trauma; findings suggest that breast cancer survivors remained resilient even when they later received bad news that their disease had spread. I wonder if this is due to flexibility in coping; are people more able to cope with more bad news when they have prior experience in changing how they coped with earlier challenges, and in turn, is this remembered as a meaningful moment so future bad news such as return of cancer is not seen as devastating as the first experience of adjusting to cancer?

Existential perspectives include Terror Management Theory (TMT) (Greenberg et al., 2004) that hypothesizes coping and resilience are linked to self-efficacy and self-esteem, and that these

constructs are used as buffers to protect against death anxiety. TMT holds that humans have a capacity to symbolically construct their own version of reality in which life has order, permanence, and stability in which they hold standards and values according to cultural worldview. This process of living up to standards and values of cultural norms is how self-esteem is acquired; for example, doing well at work and getting a pay rise boosts self-esteem in a culture that values monetary wealth. Illness is an example of how people might experience loss of self-efficacy and self-esteem, and when these are threatened people are likely to experience existential anxiety, particularly death anxiety, so coping can be viewed as the process of adjustment to changes that may result in resilience.

Another existential perspective on coping and resilience is summarized by Joel Vos who suggests; "Resilience is about the existential question how individuals are able to cope with difficult situations in life" (2015, p.62). Vos offers six assumptions underpinning the existential model of resilience:

- Humans experience existential givens such as freedom, choice, responsibility, limits and mortality.
- 2. Awareness and experience of existential givens can lead to existential moods such as death anxiety, existential guilt, meaninglessness and boredom.
- 3. Denial and avoidance are defenses used against existential moods, yet humans can simultaneously be aware that they are denying and avoiding, and this awareness can be experienced as a shock when faced with traumatic events such as a cancer diagnosis.
- 4. Existential needs for meaning, certainty, structure and freedom drive the defenses of existential moods and denial or avoidance of existential givens.
- Depending on life experience and skills, individuals can learn to accept limits,
   difficulties and uncertainties and develop a dual awareness of both the need for

- denial/avoidance and the given reality of life's challenges.
- Ineffective coping styles, such as rigidity and denial of existential givens and moods, can lead to distress and psychopathology (Vos, Joel, 2015, p.62)

Vos concludes; "Resilience seems to be at the heart of existentialism, although it is often not explicitly called 'resilience'. This opens new roads for future multidisciplinary research on existential resilience" (Vos, 2015, p.62). The existential framework for resilience resonated with me and made me think about my topic in relation to the above list. Breast cancer certainly has the potential to trigger an existential crisis; raising questions about the meaning of life, and, forcing difficult choices regarding treatment options such as mastectomy, chemotherapy and radiation which all come with global side effects that change everything about the way a woman looks and feels about herself (Williams, S., 2016). A study on existential distress in cancer confirms now life-threatening illness can challenge basic assumptions about safety, interrelatedness with others, fairness, control, certainty, and hope (Vehling & Kissane, 2018). I found only three qualitative studies from an existential perspective specifically related to women with breast cancer. The first was nursing research looking at the lived experience of having a cancer diagnosis (Halldórsdóttir & Hamrin, 1996) and the second a study exploring the meaning of existential uncertainty in a palliative care setting (Karlsson et al., 2014). The third was a Norwegian nursing study looking at coping experiences for women with primary breast cancer (Drageset et al., 2015).

However, there are many more phenomenological studies on meaning in cancer and illness. Vos (2018, pp. 222-228) outlines how illness can be a source of meaning, acknowledging that all people experience difficulties and that this is an existential given. Resilience is positioned as the ability to get though difficulties by utilizing coping, particularly coping flexibility which suggests people can and do try different strategies to cope and learn from their experiences. Vos also suggests that a source of resilience is to find meaning in life, an idea adopted from Frankl (1959)

regarding wellbeing, and how this is dependent on the ability to experience meaning even in the most difficult life situations.

Yalom (1980, p.25) proposes four basic existential concerns: death, freedom, isolation and meaninglessness. These are also known as existential givens because they are experiences that all human beings must cope with at some point during life. Strasser and Strasser (1997, pp. 16–18) incorporate Yalom's ideas and those of other existential scholars such as Martin Heidegger, Jean-Paul Sartre, Emmy van Deurzen, and Ernesto Spinelli, to provide an expanded list known as 'The Existential Wheel of Possibilities and Limitations'. Themes such as uncertainty, interpersonal relationships, time and temporality, the creation of values and systems of behavior, polarities, the four dimensions of existence, creation of self-concept and self-esteem, existential anxiety and freedom to choose, provide a summary framework to explore human lived experience from an existential perspective.

Merleau-Ponty declared that it is only through our bodies that we can experience the world, as he outlines in his observation; "perceptual life – is subtended by an 'intentional arc' which projects round about us our past, our future, our human setting, our physical, ideological and moral situation...it is this intentional arc which brings about unity of the senses, of intelligence, of sensibility and motility. And it is this which 'goes limp' in illness" (Merleau-Ponty, 1962, p.136).

Studies on the phenomenology of illness have expanded on Merleau-Ponty's ideas and have established a clear connection between illness and disruption in the sense of self, identity, and the impact of illness on how the world is experienced (Carel, 2016; Toombs, 1987; Toombs, 1990). Of particular importance is Toombs (1987) thesis that suggests all illnesses share five features described as, loss of wholeness, loss of certainty, loss of control, loss of freedom to act and loss of the familiar everyday world and that these together show the impact of illness across all lived experience or being-in-the-world.

Joel Vos (2015, pp.889-890) writes about meaning and existential givens in cancer patients drawing on the work of Martin Heidegger. It is proposed that people do not make meaning in their

lives, but instead they find meaning that is already revealed in the existential givens; and it is not until facing into, or confronting these givens, such as death anxiety in serious illness, do people have an existential crisis in which old meanings might be discarded in exchange for new ones. I am hoping that my research question will add to the body of existential knowledge about the lived experience of what it is to cope and adjust to life in the face of the challenges of breast cancer.

#### 2.5 Literature Review Discussion

Over 80% of the literature on coping and resilience with women who have breast cancer utilized quantitative methodology. The main issue I have with quantitative findings is that they can be limited because they rely heavily on self-report scales. Research suggests that some scales and instruments used to measure resilience and coping are better than others, and that even the best of them need further revision and improvement (Johnston et al., 2015). Although the findings have value, for example it is helpful to learn that wellbeing and quality of life are related to resilience, I am left wanting to know more about the role of coping. Qualitative IPA research, on the other hand, underpinned by phenomenology, hermeneutics, and idiography, offers an opportunity for researchers to get closer to the thing itself, in this case the experience of coping, by exploring and identifying detailed analysis of lived experiences (Smith et al., 2009, p.37).

My study will be a qualitative study using IPA and I am not aware of any other research using this method to explore my specific research question regarding the lived experience of coping in the context of breast cancer using the existential framework of the four dimensions. I have identified two nursing studies using qualitative methods of thematic analysis; the first researched coping with breast cancer at the specific time between diagnosis and surgery (Drageset et al., 2010) and the second explored coping strategies and experiences in women with primary breast cancer (Hajian et al., 2017). After immersing in this review of coping and resilience literature, I have not found any IPA studies conducted by psychologists with my specific questions. I hope that my research exploring the experience of coping across lived experience and in relation to time for women with primary

breast cancer can address the gap in the existential psychology literature.

# **Chapter 3 Methodology**

Methodology is a term that describes the general approach taken to research a given topic. In mainstream psychology, evidenced by the literature review in this study, there remains some allegiance to quantitative methodologies rooted in positivist and postpositivist paradigms that hold epistemological positions similar to those in the natural sciences. Quantitative methodologies embrace the view that there is a 'real world' and that we can learn about it through a scientific method (Langdridge, 2007). This position limits all valid knowledge to that which uses methods of statistical analysis to aid quantification and evidence proof. Although quantitative methodologies are helpful for certain research enquiries in psychology, such as outcome assessment research used for evidencing the effectiveness of cognitive behavioural approaches (Mahoney, 1991) they are not compatible with all research questions.

Psychology research has two main goals; first, it adds to the existing knowledge base.

Second, it offers evidence to support psychotherapeutic practice with a "commitment to scientific values and the search for truth" (Polkinghorne, 1989, p.44). Psychology research that poses questions about being human and those interested in knowing more about how people experience life and the world are the sort of impossible questions to quantify using experimental scientific methods and require qualitative methodology (Polkinghorne, 1989, p.46). Ponterotto et al. (2008) remind readers that qualitative research methods historically were used by the founders of modern counselling and psychology including, Sigmund Freud, Carl Jung, Carl Rogers, Jean Piaget and Erik Erikson, who each relied on observation and case study methodologies.

#### 3.1 Epistemology and Ontology

Epistemology is the philosophy of knowledge that seeks to understand how and what we know, grounded in ontological assumptions about people and the world. Each methodology holds

varying epistemological positions; therefore, researchers must begin thinking about their prior beliefs and what they are trying to learn to select the best methodology to fit their research questions (Langdridge, 2007; Willig, 2013).

Reflecting on the assumptions that inform my epistemological position concerning my research question was the first step in choosing the methodology for the study. The process was guided by three questions recommended by Willig (2013): First, what kind of knowledge am I trying to create? Second, what ontological assumptions such as 'What is there to know?' about the world I want to study? Third, how is my role as a researcher conceptualized, and what is the relationship between me and the study? This process helped to clarify my ideas. First, I wanted to know about the lived experience of how and what coping was like for participants with primary breast cancer. I wanted to create phenomenological knowledge about the subjective experiences of the participants. Second, I assumed that women with breast cancer have a lot to cope with and that mostly they manage, even though breast cancer is a serious illness. I mainly wanted to know how women cope in different dimensions of life influenced by my engagement with existential phenomenology and psychology. My questions had implications for the type of phenomenological research I needed to use because I sought to understand lived experiences of coping from the physical, personal, social and spiritual perspectives that would require interpretation of the meaning participants made of their experiences. Third, I considered my role and relationship to the research. I am passionate about the topic because it is personally meaningful to me. It would be impossible to bracket out my prior knowledge of life, as a woman with breast health issues, as a former nurse, a friend of women with breast cancer, and as a trainee counselling psychologist who has worked in psycho-oncology. I needed to find a methodology that allowed me to participate as a reflexive researcher, which pays close attention to the data and acknowledges the impact of how the researcher interprets the data.

This reflexive process enabled me to review quantitative methodologies and narrow down the options for this study to phenomenological methods and grounded theory. Both were considered in relation to their epistemological positions before the final decision was made to select

a phenomenological method, and finally, IPA (Smith et al., 2009; Smith & Osborn, 2015) because it is an interpretative, hermeneutic approach to phenomenology instead of the descriptive Husserlian approach of Giorgi and Giorgi (2003).

#### 3.2 Grounded Theory

Grounded theory is a qualitative approach that can develop a framework or a theory to understand phenomena better. The method originated with sociologists Barney Glaser and Anselm Strauss (1967), and it was later modified by Strauss and Corbin (1998) and more recently, Charmaz (2000) offered a constructivist revision (Creswell, 2007; Willig, 2013). I reviewed the grounded theory of Strauss and Corbin concerning this project.

Strauss and Corbin define qualitative research as "any type of research that produces findings not arrived at by statistical procedures or other means of quantification" (1998, p.11). Grounded theory qualitative analysis can be used to study a wide range of phenomena from lived experience to interactions between nations and explain that the data analysis is interpretive (Strauss & Corbin, 1998). The data interpretation is a systematic procedure used to find concepts and relationships that can be organized "into a theoretical explanatory scheme" and the resulting theory will be evidenced by the fact that it is grounded in the research data findings (Strauss & Corbin, 1998, p.11). Grounded theory is a practical methodology when a theory is not available to explain a process. It is best used with research questions focused on understanding the experience of a procedure or to identify steps in a process. This type of design usually requires as many as twenty to sixty interview participants (Creswell, 2007, p.79).

Willig (2013) explains the epistemological and ontological positions of grounded theory.

First, she observes that it holds positivist epistemology that avoids questions of reflexivity in the quest for knowledge that describes and identifies social processes. In particular, the researcher must avoid imposing meanings on the data by bracketing out prior knowledge. For example, this includes not reviewing the literature before commencing the research and holding an open question that

might change as the process unfolds, to produce a theory grounded in the data that is not influenced or dependent on external concepts introduced by the researcher. Second, grounded theory studies hold realist ontology assuming an objective reality that can be observed by the researcher. Third, the role of the researcher in grounded theory sits in a witness observer position. Thus, the researcher avoids bringing their assumptions to the analysis to give a clear view of the reality of the study.

It was clear to me at this point that grounded theory would not be a feasible option for this study because it was not aligned epistemologically with the research question. Furthermore, given my potential insider perspectives, I felt it would be impossible to bracket these experiences as required for this method.

### 3.3 Descriptive Phenomenology

Descriptive phenomenological approaches aim to identify the phenomenon's essence through epoché, intentional analysis and the psychological phenomenological reduction (Giorgi & Georgi, 2003; 2008). The Husserlian idea to 'return to things themselves' focuses on the correlation between the noema or the 'what' of experience and the noesis or the 'how' of experience. Data is collected using maximum variation sampling; this means recruiting people with a shared experience but who vary as widely as possible demographically (Polkinghorne, 1989). One criticism of this sampling method is that it can make it difficult to recruit the sample (Langdridge, 2007). Data collection methods rely on written accounts by participants or semi-structured interviews describing everyday lived experiences. The process of analysis relies on assuming a phenomenological attitude, meaning that the researcher has to bracket all previous knowledge about the topic of research and hold the epistemological position that the phenomenon under consideration is not real, but only something experienced by the participant (Giorgi & Giorgi, 2008).

Although there are similarities between descriptive phenomenology and IPA in that both methods can be used to address experiential research questions, there are differences between the approaches. The most important difference is the purist Husserlian method utilized by descriptive

phenomenology such as the concept of the researcher bracketing all preconceptions to avoid researcher interpretation. Whereas IPA is grounded in hermeneutic phenomenology based on Heidegger's ideas that question the possibility of any knowledge that is not derived through an interpretative stance (Smith et al., 2009; Smith & Osborn, 2015). I believe it would have been impossible to accomplish complete bracketing of my prior knowledge related to my research question in this project given the close ties the researcher has to the subject under investigation; therefore, descriptive phenomenology had to be excluded as a potential method for this study.

### 3.4 Structural Existential Analysis (SEA)

Structural Existential Analysis (SEA) was proposed as a research method in 2015 after years of clinical practice using the existential models of the four dimensions, the emotional compass, the concept of time and working with polarities between tensions and paradoxes (van Deurzen, 2015; van Deurzen & Arnold-Baker, 2005). These models had accompanied research enquires long before the approach became a method of phenomenological research in its own right (van Deurzen, 2015). SEA offers guidelines for an existential exploration of phenomena through heuristic stratagems that include existential models, bias awareness using three levels of intentional reduction based on the work of Husserl, and hermeneutic interviewing to collect data for analysis. To date, SEA has mainly featured as a secondary level of analysis in tandem with other more established qualitative methods such as IPA (Smith & Osborn, 2015), but more recently is emerging as a stand-alone methodology.

I considered using SEA as a secondary research method; however, I had three main concerns about its application in this study in tandem with IPA. My first concern is the similarity SEA appears to have with descriptive phenomenology, particularly the influence of Husserlian practices such as maintaining the stance of epoché. Epoché involves the idea that it is possible to completely bracket out prior understanding of a phenomenon to see things from a new point of view, avoiding researcher interpretation. In contrast IPA is based in hermeneutic phenomenology grounded in Heidegger's view that questions the possibility of any knowledge that is not derived through an

interpretative stance (Smith et al., 2009; Smith & Osborn, 2015). I had difficulty imagining how I would be able to reconcile this fundamental difference, since IPA methodology uses an interpretative stance for data analysis, and I questioned how I could defend using two methods that appear to hold different positions regarding the analytical methods. My second concern was the lack of detail and direction from Van Deurzen (2015 p.70) on how to conduct research using SEA. Even after consulting the recommended texts, I was unable to fathom a clear structure to implement SEA as a research method, compared with the clear heuristic framework offered by Smith et al (2009) for an IPA study. Thirdly there has been criticism of SEA as a research method published in a peer-reviewed paper, calling into question one of the main underpinnings of the method. Zahavi (2019) a specialist scholar in the philosophy of Husserl, critiques van Deurzen's description of Husserlian ideas on phenomenological reduction, stating that 'van Deurzen's description has no basis in Husserl's writing'. However, he concedes that van Deurzen's interpretation of Husserl's use of three separate reductions; the phenomenological, the eidetic and the transcendental, might be of value when used to promote understanding of the use of phenomenology in a therapeutic context rather than a research context (Zahavi, 2019).

While this researcher did not use Structural Existential Analysis (SEA) as an outright research method, I decided to present my findings using the four worlds model and also consider time. My rationale for this choice is as follows. Due to the complex nature of coping and subsequently the complex data which emerged from the analysis, it was necessary to select a presentation structure that offers clarity whilst simultaneously allowing space for flexibility and deep exploration. As an existentially influenced practitioner and researcher, I have found the four worlds model to provide a clear foundation that enables phenomena to be investigated and understood deeply by focusing on human existence's physical, personal, social, and spiritual dimensions. As the findings emerged, it became clear that the participants experienced coping differently within each of these four lifeworld dimensions (van Deurzen, 2014). Furthermore, as the current study has focused on providing a deep and holistic exploration of coping during primary breast cancer, the four worlds model was deemed

the most appropriate organizational tool to present the findings. Numerous published research projects provide supporting evidence for the beneficial use of the four worlds model as a structure from which to report research findings (Bennett & van Deurzen, 2017; Gaffney, 2020; Landenberg, 2020; van Deurzen, 2010; van Deurzen, 2015).

The element of time was considered necessary in analyzing the findings of the experience of coping. Heidegger (1962) asserts that time has a three-dimensional nature, situating all human experiences in a web of time that allows us to sit in the present while simultaneously recalling the past and imagining the future. This idea has implications for coping in this study because participants had to manage their present concerns of a cancer diagnosis and simultaneously cope with their contextual personal past events and imaginal thoughts of an uncertain future. Furthermore, recent research has identified links between coping and time perspective (Bolotova & Hachaturova, 2013; Morgenroth et al., 2021) supporting my decision to explore the experience of time relating to coping for the participants in this study.

# 3.5 Interpretative Phenomenological Analysis (IPA)

IPA was established to provide an alternative method for a qualitative approach to health psychology research grounded in experiential psychology practice rather than using a social science discipline such as grounded theory (Smith et al., 2009). IPA is a phenomenological, hermeneutic, and idiographic model designed to enable a greater understanding of human dilemmas, particularly how people engage with the world. IPA is informed by existential and phenomenological philosophy, for example, Heidegger's ideas of Dasein and being thrown into the world, which infers that human perception and understanding is always entwined with situations and relationships (Smith et al. 2009, p.194). IPA is phenomenological in that it involves inviting each research participant to share their experience of a major life event, in which they engage with the experience in a reflective manner to gain a deeper understanding of what the experience means to them. It assumes that

people are sense-making, that experiences can be explored in their own terms and that meanings of experience include embodied, cognitive-affective, and existential domains (Smith et al., 2009)

IPA is an interpretive practice because it is also informed by hermeneutic theory. Schleiermacher is credited with the idea that interpretation of a text is both "grammatical and psychological" (Smith et al., 2009, pp.22-23), in that grammatical interpretation is exact and objective, a word such as dog means it is referencing a dog, but it could also be interpreted in a psychological way which also involves context and the experience or bias of the individual. For example, people who generally like dogs and would perhaps hold a mental image of a playful companion as opposed to others who had experienced an angry dog barking. Hence the word dog can be benign or loaded with meaning. IPA researchers try to make sense of what and how participants have made sense of their experiences, arriving at an understanding after a process of double interpretation of both the participants' text and the interpretation of the text. IPA theorists agree that researchers need to be aware of the potential for bias and data corruption and take into account the language and the cultural context for meaning making. However, IPA research is an interpretive method, which means that the researcher must engage with the material creating a dialogue between the researcher, data, and psychological knowledge about what it might mean to develop an interpretative account (Smith et al., 2009, p79). Since IPA is grounded in hermeneutics, Smith et al. (2009) suggest that researchers familiarize themselves with the writing of Schleiermacher (1998), Heidegger (1962) and Gadamer (1990) to grasp the finer intricacies of the theoretical underpinnings of IPA methodology.

IPA has idiographic influences in that it focuses on the particular rather than the global.

Research questions focus narrowly on the lived experience of individuals, centering on what the phenomenon is like for this person and what sense this person is making of it at this point in time.

This is achieved by microanalysis of each case and then a meta-analysis across cases.

According to Willig (2013), IPA, like grounded theory, could both be considered empiricist because knowledge of the world is acquired from experience, and both methodologies hold the view

that knowledge claims must be grounded in the data. However, IPA can produce both phenomenological and critical realist knowledge. The assumptions IPA methodology makes about 'what there is to know' is based on the fundamental ontological nature of the world and how it is impossible not to make assumptions, positioning IPA as a critical realist stance. Finally, IPA is relativist because of the centrality of the researcher to the interpretation of the data, acknowledging that the same data could be interpreted differently by different researchers. Although IPA can produce knowledge that informs understanding of how participants view and experience their world by allowing the researcher to engage with the data from an insider perspective, it also acknowledges the impossibility of complete access to the personal world of others (Smith & Osborn, 2015; Willig, 2013).

The goal of this research is to get a clearer view of the nature of coping as it is experienced by women facing a primary breast cancer diagnosis and treatment. IPA lends itself to an exploration of detailed individual accounts using a hermeneutic interpretative method of analysis. The process of reflexivity is central to IPA, which fits well with counselling psychology research values of epistemological reflexivity. Keeping a reflexive journal as part of the research process is a way of supporting the validity of the research. As the researcher, I need to ensure that I give priority to what the participants report and not to my preconceptions of what I am expecting to find. Being aware of my biases and how I might influence the research will be important information to defend the validity of the project.

# 3.6 Method

IPA was selected for this study because the researcher believes that it offers the best methodological fit with the research question, focused on the personal meaning and sense making of the experience of coping in the context of primary breast cancer diagnosis and treatment. A key feature of IPA is the "focus on personal meaning and sense-making in a particular context, for people who share a particular experience" (Smith et al., 2009 p.45). By exploring detailed individual

accounts, a clearer understanding of coping using a hermeneutic interpretative method of analysis could provide a valuable addition to the current literature and could further evidence the need for psychological therapy provision for persons facing a cancer diagnosis.

#### 3.6.1 The Sample

IPA requires the sample to be homogenous as the research question is specific to the group of interest. Homogenous sampling is purposive because it aims to achieve a sample of individuals who share the same or very similar characteristics or traits. In this case the researcher specifically focused on recruiting females between the ages of 40 and 60 years because this is the age group most women are usually first diagnosed with breast cancer (Breast Cancer Now., n.d.). All the participants met the inclusion criteria designed to recruit participants with similar primary breast cancer experiences.

# 3.6.2 Inclusion Criteria

- Female adults living in the UK between ages of 40 and 60 years
- Diagnosis of primary breast cancer
- Medical treatments such as surgery, chemotherapy and /or radiotherapy completed
- Ability to communicate in English
- Ability to give written consent to participate
- Interviews will be conducted with participants who have had a minimum of three months since last element of medical treatment but who are within two years of completing treatment.

The researcher limited the study to include only women who presented with primary breast cancer, meaning a first diagnosis of breast cancer that had not metastasized (spread) to other parts of the body. Earlier breast cancer research by Brunet et al. (2013) influenced this decision, suggesting that due to the novelty of diagnosis and treatment, women's thoughts and feelings might

be amplified following an initial diagnosis, which might not be the case following recurrence of disease. They also point out the differences between treatment for primary and secondary breast cancers. Common sites for metastatic breast cancer include the bones, brain, lungs, and liver.

Treatment for secondary breast cancer can present a wider variety of symptoms and involve diverse treatments and side-effects. This writer decided that it would be more in keeping with IPA requirements of a small homogenous sample, to limit participants only to include women with primary breast cancer within two years of ending treatment, to focus on accounts of coping related to living with primary breast cancer. This decision regarding inclusion criteria does not mean that the researcher does not have interest in, nor concern for, women with secondary breast cancer; only that the researcher recognized the need to set parameters for this study, and this writer imagines potential to replicate in future research focusing on coping in a sample of women with secondary breast cancer.

# 3.6.3 Call for Participants

After ethical approval was received from Middlesex University and The New School for Counselling and Psychotherapy (NSPC), the researcher initiated a call for participants using a recruitment poster (see Appendix C, p.223). Several national UK Breast Cancer charities and support groups were approached by the researcher asking for permission to distribute information about the study on their webpages, newsletters and on noticeboards at their physical establishments. Three organizations agreed to share information about the proposed research with their service users. This writer is grateful for the support received by Breast Cancer Haven (2019), South East London Breast Cancer Trust (SELBCT) (2019) and Breast Cancer Support Group Sussex (2019). The researcher also used social media platforms including a dedicated Facebook page and Twitter account advertising the study and inviting interested parties to contact the researcher for further information about how to participate. Participants who met the selection criteria were shortlisted and invited to give consent to be recorded while interviewed using semi-structured interviews focusing on their lived

experienced of coping during their illness, considering their experience of coping within the four dimensions of the physical, personal, social, and spiritual world views and within time.

#### 3.6.4 Study Participants

Ten participants were selected who met the inclusion criteria. All participant names were changed to protect identity. Participant demographics are available in Table 1 (see p.46). The age of participants ranged from fifty to sixty years. Nine participants identified their ethnicity as white and one as white and Mediterranean. The participants shared identity with British culture; however, five participants also held specific British cultural subgroups; Allison, Beth and Irene identified as English, Cindy as Greek Cypriot, Jean as Scottish. Each participant shared their understanding of their breast cancer diagnosis and prognosis.

The researcher felt that it was important not to dwell on exact medical terms but instead give voice to each participant's meaning infused with their unique understanding of their illness. All participants understood that their breast cancer was primary, meaning that it had not spread or metastasized. They confirmed that they met the study criteria. Their treatment had been completed more than three months before the interview and within two years of diagnosis, and that they were currently in remission with no evidence of disease. All participants shared the need to take hormone therapies (HT) and be monitored for at least five years due to risk of disease recurrence.

After an initial contact by social media, telephone or email, participants were sent copies of the participant information sheet (see Appendix B, p.221) and a copy of the informed consent document (see Appendix A, p.220). Those who agreed to participate in the study returned a signed copy of the consent form to the researcher by email and a time was agreed to meet for recorded interviews. Ethics approval was granted to conduct interviews either face-to face or online using a digital platform. Interviews commenced in November 2019. The first two interviews were conducted face-to face in private rented spaces. The third interview was managed using Skype because the participant was unable to travel to meet in person. Due to the end of year and Christmas holidays

the researcher decided to wait until the New Year of 2020 before confirming more interview dates. Unfortunately, personal circumstances delayed data collection until March 2020, and then the restrictions of the global Covid19 pandemic delayed the process of data collection further. The researcher was reluctant to seek participants during the stressful time of the pandemic social distancing restrictions and lockdown; being sensitive and aware of the potential added burden of stress many people were facing into. The decision was taken in June 2020, once the restrictions had started to ease to circulate another call for participants on the social media platforms Twitter and Facebook. A further seven interviews were scheduled and conducted online using the digital platform Zoom, bringing the total to ten participants.

| #     | Name          | Age    | Ethnicity              | Culture                   | Understanding of type<br>of Primary Breast<br>Cancer                                 | Surgery                 | Reconstruction              | Chemotherapy                   | Radiotherapy | Hormone<br>Therapy |
|-------|---------------|--------|------------------------|---------------------------|--|-------------------------|-----------------------------|--------------------------------|--------------|--------------------|
| Н     | Allison       | 59     | White                  | English                   | Stage 2  | Mastectomy              | Implant                     | o<br>Z                         | ON           | Letrizole          |
| 2     | Beth          | 09     | White                  | English                   | Lobular invasive   | Mastectomy              | Implant                     | o<br>Z                         | Yes          | Tamoxifen          |
| ĸ     | Cindy         | 57     | White<br>Mediterranean | British/ Greek<br>Cypriot | HER2 positive<br>Oestrogen negative  | Lumpectomy              | o<br>Z                      | Yes & Herceptin                | Yes          | Tamoxifen          |
| 4     | Debbie        | 53     | White                  | British                   | Stage 3  | Mastectomy              | Diepp Flap                  | Yes                            | Yes          | Tamoxifen          |
| D     | Emma          | 55     | White                  | British                   | Invasive Grade 2,<br>Oestrogen receptive   | Lumpectomy              | O Z                         | O Z                            | Yes          | Anastrozole        |
| 9     | Fау           | 52     | White                  | British                   | HER2 positive  | Mastectomy              | Implant                     | Yes & Herceptin<br>&Pertuzumab | N            | Tamoxifen          |
| ^     | Gail          | 20     | White                  | British                   | IDC &DCIS, Grade 1   | Mastectomy              | O Z                         | Yes & Herceptin                | Yes          | Anastrozole        |
| ∞     | Heather       | 56     | White                  | British                   | Primary Occult   | Lymph node<br>clearance | O Z                         | Yes                            | Yes          | Letrizole          |
| 6     | Irene         | 53     | White                  | English                   | IDC &DCIS, Grade 1   | Mastectomy              | Implant                     | Yes & Herceptin                | N            | Tamoxifen          |
| 10    | Jean          | 53     | White                  | Scottish                  | Grade 2 Invasive   | Mastectomy              | Lassimus Dorsi<br>(LD Flap) | None                           | None         | Tamoxifen          |
| Table | 1. Participan | ıt Den | ographics incluc       | Jing Primary Brea         | Table 1. Participant Demographics including Primary Breast Cancer Treatment Regimens | imens                   |                             |                                |              |                    |

#### 3.7 Ethical Considerations

After gaining informed consent (see Appendix A, p.220), each interview was recorded to collect data and then transcribed and carefully analyzed as per IPA protocol to discover themes, meanings, and essences of the experience under investigation. All recordings were deleted after verbatim transcription completed. All transcriptions and notes related to the research project have been kept confidential, the names coded to make anonymous. Computer files have been password encrypted and physical files kept in a locked cabinet as per British Psychological Society (BPS) research ethics standards. As per policy of The New School for Psychotherapy and Counselling (NSPC) and Middlesex University, digital copies of anonymized data will be securely retained by NSPC for a period of ten years.

Ethical considerations also included transparency about the research project provided in the participant information sheet and the process of informed consent. The researcher had awareness and respect for the sensitive subject matter and the possibility of vulnerability of the participants, taking care to safeguard and cause no harm. For example, if a participant became distressed the interviewer enquired if they needed a break, or if they wanted to stop the interview. The researcher was aware of the power dynamic in the relationship between researcher and participant and avoided misuse of power. The researcher treated participants with dignity and their voluntary participation was valued. At the end of each interview participants were debriefed and provided with debriefing documents with a list of community resources (see Appendix D, p.224 and Appendix E, p.225). No participants withdrew from the study and no distress was reported by the participants during the debrief at the end of each interview. Participants did express how they were happy to have been able to take part and assist with the research project reporting it as a legacy, a way to give back and to help others with breast cancer in future.

#### 3.8 Reflections on the interview process

Each semi-structured interview was guided by a list of questions designed to illicit information about how participants viewed their experience of coping during their breast cancer journey. The questions were guided by the researcher's interest in the experience of coping using an existential lens; informed by the writing of Emmy van Deurzen's (2010, pp. 140–141) Four Worlds of Existence, the researcher posed questions focused on the physical, personal, relational and spiritual worldviews. In addition, other existential questions concerning the perception of time, and perception of sense of self invited participants to share their experiences comparing life before and after their breast cancer diagnosis to discover what was important, what was meaningful and how they coped with adjusting to change.

The following list of questions were utilized to guide the pace and ensure similar content of each interview. The questions were open ended, and this allowed space for each participant to provide their unique interpretation of the questions sharing their individual views on their experiences. Sample questions included:

- When you first got the news that you had breast cancer what impact did it have on you?
   Looking back how did you manage this? Was it helpful? What was unhelpful?
- Describe your physical experience of coping in relation to your cancer treatment. How did your body respond to the treatment? How did you manage side effects of treatment? How do you feel about your body now?
- Describe your social experience of coping while you were undergoing cancer treatment. How
  did your cancer diagnosis affect your relationships with others? How did your cancer
  experience affect how you were in the world with others? For example, if you continued to
  work what was that like for you?
- What was your emotional response to your cancer diagnosis and treatment? How did you
   manage difficult emotions like worry, fear and anger? Do you think cancer has affected your

sense of self?

- Have your beliefs and values about things that matter to you changed during your cancer treatment? What beliefs or values do you hold now after you have had breast cancer?
- Did this experience affect how you view time? I am wondering how you experience time now and if you have different ideas about life and death, than you did before your cancer?

Using the above list to guide each interview helped the process of data collection in that it provided a foundation of similar questions so that it the answers could be analyzed for meaning, drawing out themes and then compared for common themes across participant interviews to produce findings that came from a rigorous examination of the phenomenon.

Reflecting on the process I was aware of the timing and setting the pace of each interview. Before the first interview I was anxious about the process however I soon felt at ease and was comfortable asking the questions in a natural conversational way. One challenge I faced was keeping the focus on the questions about coping while allowing for the flexibility and natural meandering around subjects as is associated with the nature of open-ended questions. I was flexible in situations when participants spoke about topics before I asked the related questions, and I was able to move to other areas without being pedantic. The value of open-ended questions is that they allow for diversity in answers, but the interviewer is also tasked with gently bringing the focus back to the purpose of the interview to gather data about a specific topic. I experienced this in the interview with Irene, who shared a narrative about a changed relationship with family friends over a conflict between their respective adolescent sons. I remember thinking to myself at the time that this is a long story and wondered how it might be relevant to the study. Reflecting on the interview now, this emerged as useful data, the back story gave the researcher insight into how this particular participant managed interpersonal conflict in that instance. Remaining open to what emerged proved valuable. In several interviews I was aware of checking myself when listening to narratives of medical trauma, being mindful to listen without commenting or colluding to lead the participants.

One participant, Fay, mentioned her difficulties regarding mindfulness courses and I slipped up and said 'oh don't get me started about mindfulness' and I caught myself as I realized I was colluding with her belief that mindfulness courses were not helpful. I am not against mindfulness practices, but I am wary of the current pop culture mindfulness craze that I think could be potentially damaging. Leaving vulnerable people feeling like they have failed because they find it difficult to meditate after a half day course is not okay. As the interview progressed it turned out that Fay was not against all aspects of mindfulness, she just did not see the point in slowly chewing a raisin.

Recognizing the difference between the participants experience and my experience was highlighted in this example.

After each interview I wrote about my experience in my research journal. I was aware of a sense of vicarious trauma. I was reminded of earlier times in my life when working with others with breast cancer and witnessing these stories rekindled past memories. I found the process of listening to the recordings and transcribing the text both fascinating and challenging. I felt drawn to things that seemed familiar like physical descriptions of drug side effects and was careful to make sure I was staying with the text and not giving these familiar items priority. Being immersed in these stories required me to take my time and pace myself. At times it was difficult for me on an emotional level to sit immersed in the narratives. My experience transcribing the interviews was a slow process, but I feel it needed to be a slow and intense to give each text my full attention and ensure accuracy.

# 3.9 Data Analysis Method

The IPA method (Smith et al., 2009) was used to guide the analysis of the data. The researcher began by listening to each of the audio recorded interviews and then transcribing them word for word. Re-reading the transcript while listening to the recording was repeated to immerse more fully in the data. A line-by-line analysis of the verbatim text was then conducted first making initial notes of exploratory comments. These included notes of initial thoughts and observations

labeled as descriptive comments, linguistic comments, and conceptual comments. Key words and phrases were identified, and the researcher also made notes about why she thought these might be important or how they could be interpreted.

The second stage of the analysis identified and labeled the emergent themes that were developed from the text and my exploratory comments. These themes caught a glimpse of the experiential nature of coping reported by each participant. The list of emergent themes was divided and classified into connections across emergent themes. The first interview analysis was conducted using handwritten notes in the margins of a Microsoft Word © document of the line numbered transcript of raw data text. This proved to be cumbersome and difficult to track due to the large amount of data that needed to be managed. For example, the first transcript produced over eighty initial themes. The researcher made the decision to migrate the data from Microsoft Word © to Microsoft Excel © to organize and manage the data more effectively.

The third level of analysis introduced more structure into the process. Super-ordinate themes were derived from connections across emergent themes. At this stage a summary table was created showing superordinate themes for one participant. These themes were held loosely as I engaged with the process of analysis with each of the following transcripts. It was impossible to completely bracket them out, but I tried to look at each case with fresh eyes, allowing each of the ten transcripts to speak for themselves, retaining the individual voices of each participant before interpreted data was integrated to identify the final superordinate themes and subthemes across cases that are reported in the findings.

The interpretation of the data involved a circular process of making meaning from the texts. Starting from the position of the researchers' presuppositions then immersing in the data texts, the researcher tried to make sense out of the participants making sense out of their remembered experiences of coping. This analytic process was repeated for each of the ten participant interviews. Managing the data with Microsoft Excel software enabled the researcher to track and organize the data by emergent themes, connections across themes and superordinate

themes and was particularly useful when comparing data across cases. The ability to use multiple spread sheets proved invaluable to integrating data across cases because the researcher was able to maintain clarity, knowing which participant said what, in which interview, and on the specific line in the transcript. Extracts from spreadsheets showing how interview data was organized during analysis stages are available in Appendix F (see p.226).

The next step was to look for and identify patterns across cases considering both similarities and differences. This process developed the final themes that emerged allowing for both shared higher order experiences and retaining the individual voices of the participants specific experience of the shared phenomena. Data of the findings is summarized in Table 2 (see p.54).

# 3.10 Validity

IPA can produce credible, ethically sound, quality research that can stand up to scrutiny and meet criteria such as the four principles for assessing qualitative research outlined by (Yardley, 2015). My research process was sensitive to the context in that I included socio-cultural settings, drew on existing literature and used interview data from consenting participants. It meets standards for commitment and rigour because I selected a homogenous sample and conducted good quality interviews that provided a rich source for data analysis. As expected in IPA studies, I have given clear, detailed descriptions of processes beginning with an initial research proposal, then a pilot study after the first interview analysis, and have presented this thesis in a manner to ensure transparency and coherence to standards.

# **Chapter 4 Findings Across Participant Interviews**

Within the interviews, the diagnosis of primary breast cancer was a significant life event for each participant, perpetuating the need to cope with change across all dimensions of lived experience, the physical, personal, social, and spiritual. In addition, participants faced altered perceptions of time and confronted realigning their values in the face of existential concerns. The

analysis of the participant interviews, guided by an existential framework and informed by coping theories, produced findings that fall into five super-ordinate themes that inform the research questions posed by the researcher. It is important to acknowledge the distinction between the lived experience of breast cancer and coping with the impact of those experiences. The study findings reveal the lived experiences of participants, reported with explicit examples showing how participants coped in their individual contexts.

The first super-ordinate theme addressed coping in the physical dimension, revealing the embodied experience of illness and coping with treatment side effects, both in the short and longer term. The second super-ordinate theme focused on coping in the personal world, detailing experiences of the psychological impact of primary breast cancer. In the short-term participants coped with initial shock, then in the longer-term they coped with fear of recurrence of disease. Participants also reported experiencing an altered sense of self, requiring them to adjust to loss of health and cope with a new identity as a person with cancer. The third focuses on managing within the social dimension, particularly the experiences within interpersonal relationships; with family, friends, medical professionals and in work colleagues. Participants reported the use of meaningfocused coping to navigate interpersonal relationships and the ambiguity they encountered in the gaze of others. The fourth section shines a light on the spiritual dimension, viewing coping as an effort to find meaning in the breast cancer experience, realigning values while facing into the existential givens of life. The fifth super-ordinate theme addresses the participants experience of time, particularly the speed of time depending on the context, outlining how they coped by choosing how to make the best use of time and turning to hope, as they acknowledged the limits of life and the possibilities of the future.

Table 2 (see p.54) shows the findings listed as super-ordinate themes and Table 3 (see p. 55) outlines examples of ways of coping showing the number of positive responses. The reader can find selections of raw data from the interviews in Appendix F (see p.226). Participant interviews and line numbers are referred to in the text as (interview number: line number(s)), e.g. (#1:4). Access to raw

data transcripts if required is available by contacting NSPC who will hold copies securely for ten years from date of thesis.

| Physical Dimension               | seY InnoO | Personal Dimension  | seY Inno | Social Dimension                | seY JunoO | Spiritual World                | seY JunoO | Time                          | seY fruoD |
|----------------------------------|-----------|---|----------|---------------------------------|-----------|--------------------------------|-----------|-------------------------------|-----------|
| Changed body                     | 10        | Altered sense of self   |          | Meaning in being cared for      | 10        | Death anxiety                  | 10        | Realigning priorities         | 10        |
| Pain                             | 10        | Body Image  | 10       | Meaning in medical care         | 10        | Beliefs and Values             | 10        | Limits of time and mortality  | 10        |
| HST                              | 10        | Identity  | 10       | Making ordinary meaningful      | ∞         | Choice and Responsibility      | 10        | Meaning in time               | 10        |
| Surgery & Trauma                 | 10        | Lost confidence   | ∞        | Meaning in work                 | 7         | Spiritual practices            | 6         | Choosing to live purposefully | 10        |
| Fatigue                          | 7         | Worldview   | 7        | Gaze of the other               | 7         | Spiritual meaning              | ∞         | Ambiguity in time             | 6         |
| Chemotherapy                     | 2         | Values  | 9        | Meaning in caring for others    | 9         | Existentail anxiety            | 7         | Future                        | 6         |
| Radiotherapy                     | 2         | Meaning Focus   | 9        |                                 |           | Meaning in nature              | 9         | Speed of time                 | 6         |
| Lost Physical Ability            | 4         | <b>Psychological Repurcussions</b>  |          |                                 |           | Making ordinary meaningful     | 9         | Experience of waiting         | 6         |
| Positive views                   | 4         | Fear  | 10       |                                 |           | Sprituality as energy          | 2         | Present                       | ∞         |
| Lymphoedema                      | 3         | Anger   | 10       |                                 |           | Continuing bonds with deceased | 2         | Timing of support             | ∞         |
|                                  |           | Ambiguity   | 10       |                                 |           |                                | 2         | Yearning for past life        | 2         |
|                                  |           | Trauma  | 10       |                                 |           |                                |           |                               |           |
|                                  |           | Body focus  | 10       |                                 |           |                                |           |                               |           |
|                                  |           | Loss  | 6        |                                 |           |                                |           |                               |           |
|                                  |           | Positive feelings   | ∞        |                                 |           |                                |           |                               |           |
|                                  |           | Ambivalence   | 7        |                                 |           |                                |           |                               |           |
|                                  |           | Guilt and shame   | 2        |                                 |           |                                |           |                               |           |
|                                  |           | Anxiety   | 2        |                                 |           |                                |           |                               |           |
|                                  |           | Mood  | 4        |                                 |           |                                |           |                               |           |
|                                  |           | Vulnerability   | 4        |                                 |           |                                |           |                               |           |
|                                  |           | Frustration   | 2        |                                 |           |                                |           |                               |           |
|                                  |           |   |          |                                 |           |                                |           |                               |           |
|                                  |           |   |          |                                 |           |                                |           |                               |           |
| Table 2. Study Findings listed a | is Supe   | Table 2. Study Findings listed as Superordinate and subthemes with number of positive responses from participants | umber    | of positive responses from part | iicipants |                                |           |                               |           |

| Coping in Personal Dimension                     |
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| 5  |
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#### 4.1 Super-ordinate Theme 1: Coping in the Physical Dimension

Coping in the physical dimension revealed findings focused mainly on embodied implications of breast cancer treatment. Participants offered detailed descriptions of how they experienced cancer treatments, especially how their bodies coped with the side effects of treatment. In addition, an existential understanding of the physical world incorporates much more than physical embodiment; humans live in a world of objects within complex systems that need to be navigated and coped with continuously. Access to medical care, proximity to locations of hospitals and treatment centres and encountering the alien world of medical systems also need to be considered within the phenomenon of coping in the physical dimension. Medical equipment can appear as frightening and foreign objects. For example, dealing with being thrust into situations that needed to be understood, with little time or choice to comprehend, was perceived as a stressful experience.

Participants shared what it was like to cope physically with breast cancer treatments and the impact of side effects experienced in both the short and longer-term. The demands on the physical body from breast cancer treatment varied across a continuum depending on multiple variables, including but not limited to the individual's definitive diagnosis and types and combinations of treatment options. Medical advances in the treatment of primary breast cancer now allow for a tailored approach to treatment planning to meet the specific needs of individuals, making the phenomenon of physical coping a broad topic for investigation. However, the findings of this study reveal how participants who shared common treatment modalities coped with similar challenges.

As is evident in Table 1: Participant Demographics (see p.46), the list of types of breast cancer is as diverse as the individual participants. Despite the individual differences, there are also shared experiences across and within the sample. All participants underwent a surgical procedure on their affected breast and had lymph nodes under the arm of the affected breast removed to ascertain if cancer cells had invaded the lymph nodes. The implication of lymph node involvement guides oncological treatment planning. Seven participants had mastectomy procedures. Four out of

seven participants opted for immediate reconstruction with an implant. Two opted for reconstruction using tissue flaps from other body areas, and one participant opted to have a mastectomy without breast reconstruction. Five participants needed to have chemotherapy treatment. Six participants required radiotherapy treatment, and all participants were prescribed hormone therapy (HT) for a minimum of five years.

All participants received their breast cancer diagnosis while still physically healthy and had no apparent disease symptoms. Eight of ten participants were diagnosed after routine mammography, an early detection intervention offered in the UK to all women over fifty. Beth shared how an ambiguous physical change in her breast tissue, a slight dimple near her nipple, prompted her to visit her family doctor, resulting in a referral to specialist breast health services for investigation. This finding points to the elusive nature of breast cancer, showing how it can be difficult for women to detect breast cancer in the early stages, when it is most treatable, by self-examination techniques alone. Fay described her initial experience: "I had gone from being what I thought was a well person to finding a lump" (#6:66), highlighting her experience of a sudden transition from the familiar into the unknown territory of having cancer. The psychological impact of diagnosis, particularly shock and disbelief, will be addressed in greater detail under the Superordinate Theme 2: Coping in the Personal Dimension (see section 4.2 p.78).

Table 4 (see p.58) summarizes the analysis of the findings within the physical dimension.

Each theme is cross-referenced, showing the number of participants who reported similar data and how many of the topics each participant experienced as they coped with their treatment for primary breast cancer.

### 4.1.1 Experiences of a Changed Body

Across the group of participants, each shared evidence of the impact of having a changed body, see Table 5 (see p.59). Allison, Beth, and Cindy shared new perceptions of their breasts. Allison sees herself as a 'Picasso woman' metaphorically describing the uneven appearance of her breasts

as she looks upon her reflection in the mirror (#1:97-100). Not only does Allison cope with an altered body, but she also bears witness to this change daily. Beth concurs with her less descriptive but equally frank statement that after a mastectomy, "your body changes and your boob is different" (#2:280). Cindy has become more protective of her affected breast, calling it "the injured breast that can't be touched" (#3:166). Cindy also struggles with her general appearance since having chemotherapy, seeing herself as 'an ugly freak' because of hair loss related to chemotherapy drugs (#3:155-157). Hair loss impacted Fay and Irene in slightly different ways. Having a runny nose took on a new meaning for Fay after losing her body hair during chemotherapy. She relates the temporary loss of hair in her nasal passages to losing control of her body fluids (36:116-117). Irene, like Cindy, describes her experience of the permanent loss of her eyebrows, changing the look of her face (#9:602).

| Physical Dimension    | #1 Allison | #2 Beth | #3 Cindy | #4 Debbie | #5 Emma | #6 Fay | #7 Gail | #8 Heather | #9 Irene | #10 Jean | Count Yes |
|-----------------------|------------|---------|----------|-----------|---------|--------|---------|------------|----------|----------|-----------|
| Changed body          | Yes        | Yes     | Yes      | Yes       | Yes     | Yes    | Yes     | Yes        | Yes      | Yes      | 10        |
| Pain                  | Yes        | Yes     | Yes      | Yes       | Yes     | Yes    | Yes     | Yes        | Yes      | Yes      | 10        |
| Hormone therapy       | Yes        | Yes     | Yes      | Yes       | Yes     | Yes    | Yes     | Yes        | Yes      | Yes      | 10        |
| Surgery & Trauma      | Yes        | Yes     | Yes      | Yes       | Yes     | Yes    | Yes     | Yes        | Yes      | Yes      | 10        |
| Fatigue               | No         | Yes     | Yes      | Yes       | Yes     | No     | No      | Yes        | Yes      | Yes      | 7         |
| Chemotherapy          | N/A        | N/A     | Yes      | Yes       | N/A     | Yes    | N/A     | Yes        | Yes      | N/A      | 5         |
| Radiotherapy          | N/A        | N/A     | Yes      | Yes       | Yes     | N/A    | Yes     | Yes        | N/A      | N/A      | 5         |
| Lost Physical Ability | Yes        | No      | No       | Yes       | Yes     | No     | No      | No         | No       | Yes      | 4         |
| Positive views        | No         | No      | No       | Yes       | No      | Yes    | Yes     | Yes        | No       | No       | 4         |
| Lymphoedema           | No         | No      | No       | No        | No      | Yes    | Yes     | Yes        | No       | No       | 3         |
| Count Yes             | 5          | 5       | 7        | 9         | 7       | 7      | 7       | 9          | 6        | 6        |           |

Debbie described the ambiguity in her body, having a breast that "is not mine, but it is mine", one that feels "unnatural and very different". Debbie also reported her lost sense of touch, affecting her arm and reconstructed breast tissue (#4:570-572). Debbie coped with the ambiguity she experienced with her lost sense of touch in her reconstructed breast and arm after surgery by worrying about her current state of embodiment and about her future. Debbie reports how at first

she felt that she did not cope well, reporting psychosomatic symptoms such as sleepless nights and grinding her teeth at night (4:445). Debbie recognized how worrying was negatively affecting her, so she coped by seeking reassurance from her medical team.

| Participant | Line#    | Transcript  |
|-------------|----------|---|
| #1 Allison  | 97 - 100 | I have no feeling in it because all the nerves have gone. I say to myself I am a bit like Picasso woman — because I have a normal breast on this side I have had four children it's not perky you know its normal and the other one is decidedly perky, you know when I take my bra off that stays where it is this one will go down to a different level so I look at myself in the mirror and go (sigh) Oh GodI've got no feeling in it at all nothing. |
| #2 Beth     | 280      | umm when you've had a mastectomy and your body changes and your boob is different   |
| #3 Cindy    | 166      | I feel like this is the injured breast that can't be touched or you know so, that's how it feels.   |
| #3 Cindy    | 155-157  | I feel like an ugly freak. I'm sorry I, have to be honest, because I am in the small 1 – 2% that the Taxotere has affected my hair, so this is the growth from a year. Umm I am now partially bald at the back so I am in that 2%, um my eyebrow hasn't, haven't grown back, my skin is still very bad. It has gone very dry, um  |
| #4 Debbie   | 570-572  | this whole part of my body, here is just a constant reminder that it is not mine. But it is mine, but it's not the natural, it's not how it is meant to be, it feels very, very different to the rest of my body and I don't have any feeling in my arm or my boob, you know. You could touch me and I wouldn't feel it. And  |
| #5 Emma     | 874-876  | I'm struggling because I've put a lot of weight on so I'm struggling with that is one of the and and I was thinking about stopping my tablets, because of how I look and how I feel about myself, and that's huge. That is a huge thing for me.   |
| #6 Fay      | 116-117  | Sore nose. The runny nose. Um. To the ext to the point that I could be standing there talking to someone and then just the stuff would just fall out of my nose. Yeah. you've got no hair you know, obviously up your nose anymore. Um  |
| #7 Gail     | 520      | Trying to find a bra that, that fitted properly and a prosthesis that was comfortable.  |
| #8 Heather  | 38       | Oh yes. I have ended up with lymphoedema in my left arm, which is just a nice little added extra, and it's not bad though,  |
| #9 Irene    | 602      | cos I lost my hair and my eyebrows, and they haven't really come back   |
| #10 Jean    | 131-132  | Emmmm because it has changed what I can do and what I can't do and I just,., I just thought they would do the surgery and then everything would go back to the way my life was. And I'm, I was struggling with the fact that life had changed, that was quite Difficult (crying)  |

Table 5. Participant experiences of a changed body

Jean points to the impact of her changed body on her physical abilities, and her need to come to terms with her physical limits (#10:131-132). Using several different coping strategies Jean adjusted to the physical limits she faced after surgery. For example, Jean used problem solving coping to manage her initial surgical wounds (#10:149-150). However, it was later when Jean realized that her body would never return to its pre-surgical physical strength and ability that she faced a crisis. Jean shared how she felt angry with herself for not knowing how the surgery would impact her physically and how the loss of strength in her arm frightened her (#10:129). Jean used worry, rumination, tension reduction (such as crying) and self-blame as she tried to come to terms with these life-altering events. At the same time Jean also coped by focusing on the positive and acceptance of the scars on her body. Jean described how the action of rubbing E45 cream into her scars helped her to look at and touch her body and this act of self-care helped her to accept the changes.

Gail elected not to have reconstructive surgery after her mastectomy. The implications of this decision have left her trying to maintain her feminine body shape by wearing special bras that can accommodate breast prosthetics. These items can be difficult to source for a comfortable fit (#7:520). Gail used problem solving coping to manage the physical loss of her breast by sourcing and wearing bras with a prosthetic breast. Gail spoke about finding a bra that was comfortable because discomfort was a constant reminder of her lost breast and cancer. However, Gail also admits that part of this behaviour is about pretending she still has two breasts, explaining how she wears her bra during sex with her husband; "I prefer to keep my bra on (to) convince myself that I've got, you know, sort of two boobs, rather than take it off" (#7:339). Wearing her bra during sex affords Gail the ability to pretend and deny the loss of her breast and avoid thinking about cancer.

Lymphoedema is a complication that can occur after surgery or radiotherapy treatment resulting in swelling and changes in the shape of breast tissue and the arm of the affected side. The tone of Heather's statement sums up her feelings of disdain, "I have ended up with lymphoedema in my left arm, which is just a nice little added extra" (#8:38). Her sarcasm points to the facticity of her

Lymphoedema for Heather is an added chronic physical burden. Heather shares how she knows that she ought to wear a compression sleeve to prevent swelling in her arm but in the same breath she admits that she does not often comply with the recommended treatment (#8:40-41) only wearing her sleeve when her lymphoedema flares up. This type of coping is an example of an ignoring the problem, an avoidant coping style using the strategies of denial and behavioral disengagement. Then when Heather chooses to comply and wear the sleeve she copes by focusing on solving the problem.

These examples of adjusting to bodily changes point to the diversity of the impact of breast cancer treatment and how changes in the body impact not only on a physical level but also emotionally and interpersonally.

#### 4.1.2 Hormone Therapy

All participants in the study reported hormone therapy (HT) as part of the treatment protocol. Reported side effects included dry skin, vaginal dryness, bone pain, fatigue, loss of libido, discomfort during sex, hot flushes, leg cramps and emotional liability. These symptoms are like regular menopause during the natural ageing process for women; however, unlike the gradual decline in menopause, drug-induced changes occur rapidly. The side effects of HT illustrate the added layer of complexity challenging women physically.

Allison's experience of loss of libido related to hormonal imbalance side effects of HT intertwined with her changed body image. Although Allison's husband is supportive and loving, she struggles to make sense of her loss of sexual feelings:

"The lack of physical response in me is just, I wouldn't care if I never had sex again honestly, just doesn't matter, that's the way I feel at the moment because I don't feel anything, so there is a cutoff... I am completely separate from what's going on in here [points to body]" (#1:202-204).

Initially Allison coped with her loss of libido by avoiding sex with her husband. She describes how she coped by disengaging from her body, recognizing her physical being as separate from her mind. This could be interpreted as coping by ignoring the problem or denial of her sexual needs. Later Allison turned to a problem-solving strategy to cope with her dilemma by seeking individual professional counselling to address her perception of disconnection between mind and body.

Beth experienced symptoms of vaginal dryness due to HT. The loss of natural moisture required her to engage with a problem-focused coping style to source and use artificial lubrication for comfort during sexual activity. Beth mentioned the implication of discomfort during a gynaecological check-up; "even having the smear was a lot more painful" (#2:313). Beth's insight is an important finding for clinical implications. It is important for clinicians to think on the potential meanings of vaginal dryness for women on HT after breast cancer. The side effects of vaginal pain and discomfort could hold implications that could impact on other preventative women's health matters, such as avoiding future gynaecological check-ups.

Debbie spoke about her experience with HT; "That obviously put me into the menopause, straight away. Um. And... it has caused... massive hot flush problems. Um. And I am under, er, a specialist, a hormone specialist" (#4:256-257). Debbie sees her hormonal imbalance and hot flushes as restrictive, particularly impacting her ability to exercise. Debbie explained, "I like to go walking a lot, so I organise lots of walking. Um... I'd like to get fit again, but I can't, I've...with these hot flushes" (#4:462). This statement is ambiguous; Debbie is talking about her past activities in the present tense; she wishes she could get fit again, indicating hope for her future while at the same time acknowledging her limits governed by her hot flushes. Debbie uses opposing ways of coping simultaneously. She uses wishful thinking as a way of coping to reconcile her past way of being with hope for her future while also dwelling in the negative thoughts, acknowledging how her side effects stand in the way of her goals of returning to physical fitness.

Like Debbie, Heather also suffers from hot sweats related to her medication; "I've been sat here like, moments I've wanted to fan myself, as I have the, what I call turbo charged menopausal

hot sweats" (#8:966). Heather's humour, laced within her detailed description, reveals her use of humour to make light of and cope with a difficult situation. Although humour does not solve problems, it can ease emotional tension and concurrently allow space for cognitive restructuring.

Emma described her experience of HT: "I think my body has [had] a shock, and I think I didn't adapt very... I have not adapted very well to the Anastrozole" (#5:213). Emma struggles with an altered body due to weight gain, which she blames on the medication and wonders: should she stop taking medication that might save her life because she can't bear being overweight? (#5:874-876). Emma connects her weight gain to her medication and has contemplated stopping her drugs because she does not like the side effects. Emma has anxiety about her need for physical fitness to return to work as a police officer. She worries how she will cope when "sometimes I can't walk to the end of the street... So, I think, how am I ever going to be physically able to... be fit at work again" (#5:602-604). Emma judges herself as not coping well with the side effects of her medication. Emma copes by worrying and ruminating about her current issues and the impact they might have upon her future. Worry appears to serve a purpose to allow Emma space to consider her options. Emma considered using a problem-solving approach by stopping her medication. Although that might have solved her current problem, Emma also sees that this is not in her best interests because the tablets might prolong her life expectancy. This example illustrates the complex nature of coping and how individuals can be in a constant state of flux as they navigate their way through ambiguity in their lived experiences.

Ironically Gail's breast cancer was discovered during tests with a functional health doctor she consulted for managing menopausal symptoms. Gail expressed concerns about her thinning hair but, more importantly, is reluctant to rely only on HT for her future wellbeing. Gail copes by continuing to seek support from functional health professionals; "I felt there needed to be something else I could do, um... but rather, rather than just... take these pills and everything is going to be fine" (#7:547). Gail copes, taking action to gain a sense of control, using a problem-solving approach to self-care.

Irene reflects on her HT experience of "being pushed through menopause early" (#9:649). The word pushed is interpreted as rushed, doing something against her will, and being out of control. Irene ambiguously shares that she has had "quite a few side effects, but not enough to make me so poorly I come off it, but just cramps at night, aching feet, hot flushes. Headaches, you...just. Just things that you, you take in your stride, and you put up with". (#9:649-652); Irene's words show how she copes by minimizing the impact of her experience, reframing it into something she can manage.

Jean gives a profuse description of her side effects of HT, and it is interesting how she laughs as she shares how she cries, making me wonder what crying means to her:

"Oh. Terrible. I'm just crying all the time. (Laughs)Ha. I just... been crying a lot. Emmm. Sweats all the time...Hot flushes all the time, can't sleep, ermm, physically there's just a lot of fatigue, um, my hands and my feet are sore...I've read somewhere that Tamoxifen affects the small bones, so it's like your hands and feet, and can be a lot of pain" (#10:415-417).

As Jean listed her symptoms, there is little surprise that she would need to cope by crying to release tension. Jean also shared how she copes with fatigue during the day due to disturbed sleep patterns using self-care such as resting. Jean utilizes problem solving coping to address what she describes as 'brain fog', sharing her way of coping by writing things down on lists to help her remember (10:439-440).

# 4.1.3 Surgery and latrogenic Trauma

Each participant in the study reported surgical complications. Allison opted for surgery involving a nipple-sparing mastectomy with immediate reconstruction using a prosthetic breast implant. Allison described her experience of surgery as a physically traumatic event. Her language "they cut my breast off" (#1:104) gives the sense of her surgery as a barbaric act. Allison shared her experience of being discharged from hospital after one night on a general surgical ward, "with drains hanging out of me that I had to empty blood and god knows what out of ...it was horrendous"

(#1:80-81,283,286-288). Allison shared that she coped initially by accepting help from others. For example, she had community nurse support who helped her manage her wound dressings and surgical drains and she allowed her daughters to help bath her and wash her hair. The longer-term impact of reduced mobility in her arm on the affected side required Allison to use different ways of coping. On the one hand she dwells in the negative fact that her arm is weaker and impedes on her ability to do her work, yet at the same time she puts this into perspective using cognitive restructuring, saying that it has only been a year since her surgery and accepts that it takes time to heal.

Beth described her mastectomy followed by immediate elective reconstruction with a prosthetic implant and excision of eight lymph nodes as "a big surgery I think it took about 5 hours, something like that' (#2:154). Although Beth's treatment plan did not include chemotherapy or radiotherapy, she did have post-surgical complications with recurring wound infections. Beth describes six months of repeated hospital admissions for intravenous antibiotic treatments:

"For some reason I, we don't know how, but I picked up an infection, so I had about 5, 6 different types of antibiotics. Then I had Insolid what they use for MRSA and stuff, I hadn't had MRSA, but it's the antibiotic of last resort, um and that...I was exhausted, fatigued umm and as soon as I got better after a basic antibiotic, it would be three weeks and boof it would all come up red again back in hospital IV's, come out 3 or 4 weeks boof come up again" (#2:174-178).

Beth's account points to living in a state of uncertainty; not knowing if or when her body would respond to efforts to ward off infection. Beth coped with her fatigue and exhaustion with self-care. She shared how she focused on resting, spending much of her time sleeping. Beth conserved her energies and did not engage in activities that did not benefit her. Beth used behavioural disengagement, a type of avoidant coping by isolating herself from well-meaning friends and family members who wanted to visit her. Beth also spoke of times when she coped by engaging in rumination and worry described as 'going down the rabbit hole'. Beth shared how she managed to

change her focus to more positive thoughts with the help of her husband who monitored her mood and coached her out of the metaphorical rabbit hole.

Cindy had a wire-guided lumpectomy to remove her tumour. Although a lumpectomy is considered less invasive than a total mastectomy, Cindy had post-surgical complications that required her to undergo a second surgery and have a blood transfusion. Cindy recalls: "I was very bruised, very very bruised. They said that they had never seen nothing like it, um, and I been left with scar tissue inside" (#3:121-122). Cindy shared her belief that she did not cope well initially, reporting how she often worried about ongoing pain and ruminated over what this could mean. Like Beth, Cindy also coped by isolating herself from others so that she could rest and recover. Cindy shared her coping strategy of 'taking one day at a time' (#3:121), explaining how she coped by pacing her activities. Focusing on self-care and rest while trying to stay in the present helped her to avoid worrying about the future.

Debbie opted for a mastectomy followed by a DIEPP Flap reconstruction involving tissue from the abdomen to fashion a new breast. Debbie saw this as the most natural option since she did not want a prosthetic implant. Debbie described her experience of surgery:

"They do the two operations in one, they do your... sort of take the fat from your stomach, um, and then they take all your lymph nodes out. Twenty of them I had, quite a lot. Um... and then they make you a new boob. Um, what I didn't realize, and they didn't tell me, was that, when they send you home, you have to do your own wound care, which was surprising because my wound opened up in the middle". (#4:183-187)

The surgery left Debbie to cope with swelling and sensations in her breast that she did not expect.

Debbie wished someone had prepared her by telling her that "it's gonna feel heavy, it is going to swell up, it's going to be sore, um.. and that's not going to go away. For years, or forever maybe" (#4:614-615). Debbie coped by dwelling in negative thoughts, ruminating as she endeavored to make sense of why she was not warned about what to expect prior to surgery. latrogenic surgical trauma left Debbie to manage daily dressings on her abdominal donor site that took months to heal. Debbie

sought professional help from her surgical team and cancer nurse specialists who taught her how to manage her wound care. Learning new skills helped Debbie cope by taking control of the things she could, to help heal her wounds. Although her wounds eventually healed, Debbie faced longer term psychological implications because she is unhappy with her resulting scars. Debbie wrestles with feelings of guilt as she questions if she would have had a different outcome if a specialist wound care nurse had tended to her post-operatively. Debbie's narrative raises serious questions about her access to outpatient wound care.

Fay rated her breast surgery experience compared to chemotherapy as relatively easy (#6:123). Fay explained her understanding that the chemotherapy had reduced the tumour size, allowing for a minor surgical procedure to remove it. Fay shared, "I liked very much the fact that I woke up with no dressings on. She'd glued me back together" (#6:128). Fay separated her surgical narrative, seeing the breast surgery as minor. In contrast, the surgical removal of the lymph nodes under her affected arm was the "bigger operation" (#6:130) due to the complication of resulting lymphoedema.

Gail opted for a mastectomy without reconstruction. During her operation, she allegedly lost blood and was very bruised afterwards. Still, she believes that her excellent level of physical fitness before surgery enabled her to cope better with her physical recovery (#7:133-134) and manage without the need for a blood transfusion: "Although I did bleed quite a lot, I lost quite a lot of blood. Not enough to need any transfusions or anything. Um... err... but I, I healed fine" (7:136). Gail, like Fay, adjusted using cognitive restructuring, coping by focusing on positive facts such as good health prior to surgery and assessing her healing process positively.

Heather was the only participant with primary occult breast cancer, meaning her cancer was found only in the lymph nodes under her arm, but it was not detectable in her breast tissue. This situation created ambiguity for Heather as she wondered how this could be true. As a result of her surgery to remove her lymph nodes, Heather, like Fay, now must cope with long term lymphoedema. Heather expressed her ambivalence about complying with recommended preventative measures

such as wearing a compression sleeve. Heather uses the strategies of denial and behavioral disengagement in this avoidant coping style.

Irene shared her dislike of the experience of coping with her surgical wound drains "it's not good where you have got to, got the... drains coming out" (#9:141). Unfortunately, Irene had ongoing wound complications; "but then I, then I had trouble, because the, even when they took the drains out, I, I kept, they kept getting swelling where fluid was building up, so I had to go back... I think it was four or five times to the hospital and have, with, the aspiration. Where they... put the needle in (#9:146-147). Multiple visits to hospital for aspiration of fluid build via needle biopsy was physically traumatic for Irene, yet her way of coping was to accept her situation and seek professional help by trusting the medics to sort out her issues. Focusing on solving the problem was Irene's coping strategy.

Jean shared her experience of healing after lassimus dorsi (LD Flap) surgery which entailed removing tissue from her back to reconstruct a new breast. Jean had to cope with complicated wound care on the reconstructed breast; "the scars.... emmm, burst open and because it's like a bullseye patch they've the kinda bottom part kind of burst open it's, was bleeding for a while, for about two three weeks, emmm, so I had that bag thing, a wound bag thing on" (#10:149-150). Initially Jean coped by solving the immediate problem and seeking professional help to manage her wound care. However, this surgery has had long term consequences for Jean leaving her with reduced physical mobility and strength in her back and arm. Jean reports different strategies to cope with these changes including denial, ignoring the problem, protecting herself and wishful thinking. For example, Jean uses wishful thinking to hold onto hope that her post-surgical disabilities will not be permanent, although as an occupational therapist she also knows that they could be. Denial strategies concerning her physical limitations are illustrated in her experience of returning to physical exercise. Jean paid the price in aches and pains after swimming and doing yoga. She pushed her body too far, denying her limits paradoxically left her in pain and ruminating in self-blame.

#### 4.1.4 Coping with Pain

Allison reported moderate discomfort and pain at the surgical site but was unable to lift up her arm (#1:86-87). Over the counter analgesia eased her physical pain while Allison had to adjust to being unable to manage daily activities like bathing or getting dressed without help from her daughters (#1:89). Although Allison described this experience as "horrible" she also managed to see the positive in her situation; "I used to think, I've got my legs I'm fine I can go up and down the stairs and make myself walk round the garden and get some fresh air just try and keep myself going" (#1.90-91). Focusing on the positive in her situation helped put her experience into perspective, one that she could manage to cope with.

Beth reported discomfort after surgery but rationalized that this was to be expected: "you know you're always sore, you'd had surgery and you got deep wounds and it has to heal from inside and there's a lot of healing to be done so um yeah you have to reevaluate what you can do" (#2:183). Beth coped with discomfort by adjusting her behavior as she tried to get "back on track" holding the goal to return to her normal life while recognizing she had undergone major surgery with "deep wounds". This is a good example of meaning focused coping using adaptive goal processes.

Cindy shared how her surgery "hurt a lot more than I thought it would. It was very, very painful and there were days when I just laid in bed and cried" (#3: 115). Cindy managed to live with pain using two strategies, she coped by releasing tension by crying and self-care by retreating to the comfort of her bed.

Debbie was discharged from hospital with a lack of sensation in her arms and inability to stand up straight due to pain. She had two wounds, one on her abdomen where the donor tissue for reconstructed breast was harvested and the second being the actual breast reconstruction. The intensity of her pain made it difficult for her to stand up straight leaving her worried that she might never stand up straight again: "After the operation, after they sent me home... it was very difficult to

stand up straight, I didn't think I would ever be able to stand up straight again" (#4:559-560). Worry is a way of coping to make sense of physical limitations, but it also holds the risk of implications for future psychological wellbeing.

Fay had to cope with peripheral neuropathic pain, an unfortunate side effect of chemotherapy leaving her with pain and numbness in her feet and fingertips (#6:83). Walking was difficult for Fay due to the pains in her feet culminating in reduced mobility: "I couldn't actually walk up the stairs, so I had to crawl upstairs" (#6:100). The pain and numbness in her fingers prevented Fay from doing simple tasks like tying her shoelaces (#6:102). Fay described a global sense of physical discomfort: "I am so uncomfortable in every area of my body. That I just... I need today to be over.... Um..." (#6:105). Escaping from the pain associated with basic activities of daily living was achieved by going to sleep. Fay coped by engaging in self-care to rest her weary body. Sleep could also be interpreted as an avoidant coping strategy.

Heather, like Fay, also must cope with peripheral neuropathy pain in her hands and feet: "I literally couldn't feel my fingertips and my feet killed me. It just really hurt and actually that has been a constant thing ever since" (#8:149). Peripheral neuropathic pain is a common term side effect after chemotherapy. Heather copes with daily reminders of the treatment she has endured, and the limits of her body illustrated by her lived experience: "Waking up in the morning not being able to put your feet on the ground, because they hurt too much (#8:964). Heather copes with her physical pain by adjusting her behavior and focusing on self-care, for example she takes breaks from typing when her fingers are sore and rests when her feet hurt. Heather copes with the psychological impact of her pain by focusing on the positive, practicing gratitude that she is still alive despite her diagnosis of cancer.

Gail also shared a sense of global body discomfort since her surgery "Cos everything feels uncomfortable, you know. Um... yeah" (#7:517). Yet Gail struggles most with pain related to her experience of lymphoedema. At the time of interview, she was not experiencing this type of pain, but she is aware that it can flare up again at any time so has become vigilant in looking after herself

and paying close attention to her body for signs of lymphoedema. Gail copes by being vigilant in looking after herself and paying close attention to her body for early signs of lymphoedema.

Irene had complications after her surgery but does not dwell on pain related to needing her wound drained by needle aspiration. Instead, Irene speaks of her pain related to her experiences of chemotherapy. Irene used a cold cap, a device intended to prevent hair loss during chemotherapy, but she does not recommend this to others due to her experience: "Cos you are so cold, and you get brain freeze, and you can't really, you know you find you are slurring on words, or not saying words properly. Um..." (#9:118) The side effects of the cold cap to try to keep hair involved physical discomfort and a loss of control over her ability to think and speak clearly. She regrets using it because it did not really work, her hair thinned on her head and she lost her eyebrows, so for Irene, the costs of using the cold cap outweighed the benefits.

Jean described painful experiences related to different stages of her cancer journey in addition to anticipated mastectomy surgical pain. Jean mentioned experiencing pain from a surgical biopsy (#10:119) and then later after recovering from surgery other pain emerged in response to doing too much swimming and yoga: "my shoulder, my neck and all down my back, it was like um, spasms in the muscles" (#10:119). Jean coped with pain by adjusting her behavior, for example limiting physical exercise after facing into the reality of the new limits of her body. Jean also practices more self-care for example massaging her scars. Jean's narrative offers helpful insight into potential risks of longer-term pain related to the LD Flap type of reconstruction surgery.

# 4.1.5 Lost Physical Abilities

Four participants struggle with longer term physical consequences related to lost physical abilities after cancer treatment. Allison cited restricted mobility in her arm and tenderness that impede her ability to do physical work such as digging (#1:161-162). Allison coped with her reduced physical strength in her affected arm using cognitive restructuring. Rationalizing this as a temporary

condition, given her understanding that it can take many months to heal after surgery, allowed Allison to accept her situation.

Jean struggles with reduced mobility and strength in her arm that impact her ability to do activities of daily living such as get in and out of a bathtub (#10:294). Jean shared that she could get into the bath but has lost the upper body strength to lift herself out again. The implication of lost mobility for Jean impacted her on several levels: she was forced to look at the limits of her physical body, particularly her inability to work as a therapeutic masseuse, leaving her to cope by dwelling in the negative as she faced into loss and the psychological implications of self-blame for choosing LD Flap reconstructive surgery. Jean coped with each of these examples in different ways. She modified her behaviour when bathing. She avoided working as a masseuse and she ruminates and blames herself for electing to have the LD Flap surgery. Although each of these ways of coping appeared to be ways to solve her immediate problems Jean felt overwhelmed by all the changes and adjustments she had to make. All of this held psychological repercussions, requiring Jean to seek professional help from a psychologist because she felt she was unable to cope.

The fear of disability was echoed by Debbie who also worried about her future both immediately after surgery when she suffered with numbness in her arm and during the long healing process due to complications at her reconstruction donor site (#4:560). Coping by worrying about present and future concerns prompted Debbie to seek advice from medical professionals, who reassured her that her symptoms where to be expected and that they would improve over time. Worrying in this case was the catalyst for taking action to solve problems.

Emma also experienced limits of her body: "you know, you have days when I can't get out of bed" (#5:851). This was particularly concerning for Emma who was physically active and able-bodied prior to her treatment. Emma coped by using protective self-care strategies such as resting and taking time off work to recuperate. Emma also used problem solving coping by reaching out and accepting support from others.

# 4.1.6 Challenges of Chemotherapy

Half of the sample had chemotherapy as part of their oncology treatment plan. Table 6., Physical Issues with Chemotherapy (see p.73), catalogues seventeen issues mentioned by participants related to their experiences in relation to their treatment. Irene had the fewest with six out of seventeen, while Fay the most with ten out of seventeen. All participants reported fatigue and loss of body hair. Four reported head hair loss, except for Debbie who reported moderate success in avoiding alopecia with the use of a cold cap during her chemotherapy infusions. Irene also used the cold cap but with a less successful outcome. Four participants had neuropathic type pain apart from Debbie.

| Chemotherapy Side<br>Effects | #3 Cindy                                   | #4 Debbie | #6 Fay | #8 Heather | #9 Irene | Count Yes |  |  |  |  |
|------------------------------|--|-----------|--------|------------|----------|-----------|--|--|--|--|
| Fatigue                      | Yes  | Yes       | Yes    | Yes        | Yes      | 5         |  |  |  |  |
| Hair loss - body             | Yes  | Yes       | Yes    | Yes        | Yes      | 5         |  |  |  |  |
| Hair loss- head              | Yes  | No        | Yes    | Yes        | Yes      | 4         |  |  |  |  |
| Nausea                       | No   | Yes       | Yes    | Yes        | Yes      | 4         |  |  |  |  |
| Neuropathapy pain            | Yes  | No        | Yes    | Yes        | Yes      | 4         |  |  |  |  |
| Altered sense of taste       | Yes  | Yes       | Yes    | No         | No       | 3         |  |  |  |  |
| Bowel issues                 | Yes  | No        | Yes    | Yes        | No       | 3         |  |  |  |  |
| PICC Line                    | No   | Yes       | Yes    | Yes        | No       | 3         |  |  |  |  |
| Brain fog                    | Yes  | No        | Yes    | No         | No       | 2         |  |  |  |  |
| Sore mouth                   | Yes  | No        | Yes    | No         | No       | 2         |  |  |  |  |
| Vomiting                     | No   | No        | Yes    | Yes        | No       | 2         |  |  |  |  |
| Acne                         | No   | No        | Yes    | No         | No       | 1         |  |  |  |  |
| Nose Bleeds                  | Yes  | No        | No     | No         | No       | 1         |  |  |  |  |
| Temperature changes          | No   | No        | Yes    | No         | No       | 1         |  |  |  |  |
| Sensitive eyes               | No   | No        | Yes    | No         | No       | 1         |  |  |  |  |
| Blood clots                  | No   | No        | No     | Yes        | No       | 1         |  |  |  |  |
| Headaches                    | No   | No        | No     | No         | Yes      | 1         |  |  |  |  |
| #Yes out of 17               | 7  | 4         | 10     | 9          | 6        |           |  |  |  |  |
| Table 6. Physical Issues w   | Table 6. Physical Issues with Chemotherapy |           |        |            |          |           |  |  |  |  |

Cindy, Debbie, and Fay each had to cope with an altered sense of taste during chemotherapy.

Debbie shared how she handled this dilemma by eating different types of food to combat her problem:

"One of the worst things was the... um... um... er... no taste buds, or everything else tastes like cardboard. Or metallic. And that wasn't great. I just, I had been, just been changed to more spicy foods, things that I could taste, and things that I could feel in my mouth. Like, crunchy, crisps. I'd like to eat because that sort of compensated" (#4:151-155).

This is an example of adaptive problem-solving, adjusting what is within one's control to meet changing needs.

The findings showed three participants who reported severe bowel reactions requiring medical intervention for both constipation and dehydration connected to diarrhea. Cindy was hospitalized due to diarrhea that left her dehydrated needing IV fluids; "I was put on a drip for three days" (#3:126). Fay reported a similar situation; "the Pertuzumab gave me um, terrible diarrhoea, and I'm talking, terrible. Um. To the extent that they kept sending me to A& E, um, because they were worried about it" (#6:193-194). Heather cited a different experience with constipation in response to the mixture of medications she was taking:

"Terrible things like constipation. (laughs) cos they give you steroids and then they give you all kinds of other stuff and then they give you co-codamol to stop the pain and of course, all that cocktail, your insides are just going WHAT the hell is happening? Um, and I felt so sick, and I didn't understand why I felt so sick, and it wasn't actually because of the drugs, it was because I couldn't go to the loo" (#8:157-160).

Heather reported going to the hospital emergency room on occasions because of vomiting due to bowel impaction caused by constipation (#8:162).

Participants reported that they had their treatment in three-weekly cycles, meaning that they would have the treatment, feel unwell for about a week, and start to feel better in time for the next round to begin. This regimen left participants exhausted, and the effects over time appear to be cumulative. Irene stated: "to a certain extent I could do my normal things anyway, apart from the

first time I had the chemo, but I just felt quite tired ...and have the next lot of chemo, you are starting from a slightly lower base" (#9:71-73).

### 4.1.7 Implications of Radiotherapy Treatment

Five participants received radiotherapy as part of their breast cancer treatment and two main findings emerged. The first shared by Fay, Gail, and Heather revealed that although they tolerated the treatment well, each now have complications related to lymphoedema. Fay shared how her problem started with swelling in her arm after the surgery to remove lymph nodes, then how after radiotherapy the lymphoedema spread to her breast as well (#6:138-139, 162-163). Fay expressed feelings of frustration with the chronicity of her lymphoedema requiring her to wear a compression sleeve and have regular lymphatic drainage massage. Fay also shared feelings of frustration with the limits of access to free lymphatic massage services that have long waiting lists and are restricted to a few visits each year. This raises important findings related to the physical world where economic advantages often make a difference in access to care to cope with longer term after-effects of treatment.

The second concern reported by Emma and Heather involved anxiety related to breath holding techniques required as radiotherapy is administered. Heather explained "you have to do this breathing so that they don't, erm... don't damage your lung and your heart when they are doing it. So um... yeah, lots of practices of breathing before I could get that right" (#8:310-311). Emma spoke of the paradox she experienced; the more she tried to get the breath holding technique right, the harder it became to relax, and she needed to relax to control her breath (#5:180-182). As Emma shared her memory of her experience, she became tearful, it occurred to me that the meaning for Emma to get this right was not limited to her ability to physically control her breath, but had wider consequences, potentially being responsible for damage to her heart and lungs if things went wrong.

#### 4.1.8 Body Positiveness

A minority of four participants framed their physical experience in positive ways, acknowledging how well their bodies coped under the stresses of treatment. Debbie looked back on her chemotherapy as an event rated as successful in that it reduced the size of her tumour by 50% (#4:56). Her appraisal framed chemotherapy as "not as bad as I thought it would be" (#4:151) even though she also reported negative chemotherapy experiences as well, like losing her eyebrows and eyelashes (#4:150). Fay reported how she found surgery easy (#6:123) compared to chemotherapy, and like Debbie credited her body for having "a complete response to the chemotherapy" (#6:127). Fay also credited her skin for holding up well during radiotherapy (#6:160) even though she also had side effects from the radiotherapy. These examples highlight how participants coped by focusing on the positive to tolerate the more difficult aspects of their experiences. They made comparisons between their imaginal expectations and lived reality, allowing them to put their experiences into perspective. In addition, these findings have implications for psychotherapy practice. Exploring events through the physical dimension can help shed light on new meaning in embodied experiences, allowing for adjustment to attitude and recognition of our position in the tensions between polarities of health and illness.

# 4.1.9 Coping with the Experience of Fatigue

The final sub-theme within the physical dimension is the experience of fatigue. Seven participants spoke of feeling exhausted in response to various elements of their treatment. Words and phrases like "washed out and wiped out" (#9:136), "constant battle" (#3:118), "a bit tired" (#4:216), "it's just draining" (#8:188) help give a sense of the phenomenon of fatigue for study participants. The most common coping behavior related to fatigue for Beth, Cindy, Jean, Irene, and Heather was self-care, retreating to the sanctuary of bed as demonstrated in Table 7 (see p.77). In addition, Beth coped by conserving her energies and did not engage in activities that did not benefit

her. She used a type of avoidant coping by isolating herself from well-meaning friends and family members who wanted to visit her. Beth also spoke of times when she coped by engaging in rumination and worry described as 'going down the rabbit hole' as she tried to make sense of the meaning of her fatigue. Beth shared how she managed to change her focus from worrying to more positive thoughts with the help of her husband who monitored her mood and coached her out of anxious moments.

| Participant | Line# | Interview Text   |
|-------------|-------|--|
| #2 Beth     | 385   | Oh yeah, no no no, Yeah there were times during the 6 months where I remember I was just sleeping all the time that's why I didn't   |
| #3 Cindy    | 118   | I was, I was very tired, very, very tired um, um, it was a constant battle for me, that is what it felt like. It was, grabbing onto small, little things to get you through. |
| #4 Debbie   | 216   | I didn't have any, side effects from the radiotherapy at all. Apart from being a bit tired.  |
| #5 Emma     | 619   | mile walk but then the next day I might not be able to just the fatigue just hits you. It's like being hit in the face with an iron like on a                                |
| #6 Fay      | 47    | I tried to do something in each of those days, that, brought me some sense of joy. Whether that was stroking the cat was all I could manage or,                              |
| #7 Gail     | 233   | Yeah, my body well, I was tired but I wasn't as tired as I thought I was going to be. Particularly the radiotherapy, everybody said,   |
| #8 Heather  | 164   | But I think it was just the constant, urgh. Just the tiredness. Getting up in the morning, moving around, getting dressed even,  |
| #8 Heather  | 168   | I slept when it was bad, I slept a lot.  |
| #9 Irene    | 125   | I am really sorry, I can't talk to you anymore. I am going to get the dog in, and I have to go to bed. And she said, oh no, that's fine.                                     |
| #10 Jean    | 281   | No, I can do it, I can do it, but I was just, I'd come home and go to my bed and be exhausted. Em. So But  |

Emma described her experience metaphorically, "being hit in the face with an iron" (#5:619), her language conjures an image of violently being stopped by her fatigue. The implication here relates not only to feeling physically drained but also the greater meaning of lost ability to do the things Emma enjoys like walking. Emma coped with her tiredness by resting but she also worried about the wider meaning of her fatigue coping by ruminating in intrusive negative thoughts about her future wellbeing.

Fay reports how she coped with her worst days by trying to engage in activity that brought her joy; her words paint an image of a woman who had days where all she could manage was to lie in bed or on her sofa stroking her cat (#6:47). Fay coped by seeking a relaxing diversion and infusing ordinary events with meaning, finding joy in small pleasures is considered a meaning-focused way of coping.

### 4.1.10 Coping in the Physical Dimension Summary of Findings

These findings give a broad overview and some detailed insight into what participants managed during treatment. In addition to the rigors of coping with physical issues such as pain, fatigue and altered bodies, from surgery and chemotherapy, participants also navigated the physical domain of hospitals and medical equipment such as wound drains and PICC lines. Others entered the world of radiotherapy, having to lie naked with breast exposed, holding their breath for fear of accidental damage to vital body organs. Everything that the participants coped with physically has connected implications across all four dimensions of existence. Participants coped with physical world issues using a variety of strategies depending on individual context and appraisal of situations. All participants used self-care, focusing on the positive, cathartic release of emotions, hope for a better future, rest, rumination, worry, seeking medical help and taking action to solve problems. The next section explores the personal dimension and how the participants coped with issues such as psychological repercussions and an altered sense of self.

#### 4.2 Super-ordinate Theme 2: Coping in the Personal Dimension

Within an existential framework, the personal dimension is concerned with psychological constructs of identity, moods, and emotions, always interconnected with the physical, social, and spiritual dimensions of life. The interpretation of participants shared experiences of coping with primary breast cancer found two sub-themes: dealing with an altered sense of self and managing psychological repercussions related to existential givens. Existential givens are facts of life, such as

freedom to choose, uncertainty, interpersonal relationships, values, tensions between polarities, time and temporality and existential anxiety. Coping with existential givens involves accepting limits by changing our attitude and finding different meaning about things that we cannot control or change.

#### 4.2.1 Coping with Psychological Repercussions Related to Existential Givens

All participants had dramatic and negative psychological repercussions as they struggled to take in the meaning of a breast cancer diagnosis and its implications for themselves on a personal level, in relationships, for future health, and life expectancy.

i) Being Thrown into the World of Breast Cancer. There was a shared psychological experience of initial shock amongst nine of the ten participants, the only exception being Jean, who was not surprised by her diagnosis. Table 8 (see p.80) summarizes words and phrases used to describe initial responses. The language and metaphors used by participants paint a vivid picture showing how their understanding of life abruptly changed in an instant. The psychological impact involved rapid adjusting to a new reality. Being thrown into a world that was not of their choosing left them to cope with a wide range of distressing emotions such as anger and fear, and later as they adjusted to their new realities, they reported calmer states of relief and gratitude. Participants had to adapt to a perceived loss of control over life as they knew it, suddenly facing how life itself was contingent on the success or failure of cancer treatments. Upon diagnosis the study participants reported different coping methods addressing their initial sense of shock. Most described initial tears, crying, emotional numbing, rumination and intrusive thoughts related to threatened mortality. After an initial cathartic release of emotion, participants reported adjusting by turning towards solving the problem, coping by seeking professional medical support.

| Participant | Line# | Transcript   |
|-------------|-------|--|
| #1 Allison  | 8     | Huge it was like being hit round the back of the head and punched in the face at the same time because I really didn't expect  |
| #2 Beth     | 84    | Yes just too big, yeah   |
| #3 Cindy    | 101   | You know. That minute, was, it was shock. I know it sounds a bit silly but I just thought, you know, this has happened to me, how had this happened?   |
| #4 Debbie   | 32    | ButI was so, like, shocked. It was very shocking diagnosis, because, well I can tell you about that if you want me to?   |
| #4 Debbie   | 47    | You could have knocked me down with a feather  |
| #5 Emma     | 92    | so I should be able to deal with things in my own life. Soumit was, it was a shock, but I think I went into mechanical mode and, they  |
| #6 Fay      | 74    | was justas you can imagine. Enormous. I, it was like I had been hot by a truck, that I couldn'tyou know.   |
| #7 Gail     | 89    | And it was absolutely like I hot a brick wall.   |
| #7 Gail     | 117   | I think it was, so, a big shock. Because I, I've, I wasn't expecting it to be cancer, I just thought they were going to say, oh it's just,   |
| #9 Irene    | 16    | The first of February 2018. Not a date you forget easily.  |
| #10 Jean    | 90-92 | I, um I, was expecting it, because I had my very first mammogram in the middle of October, then I had em biopsies in November biopsies in December biopsies in January. So, I knew, I just, I thought they wouldn't be doing this For nothing. Really. So I kind of knew so when she told me it wasn't a surprise. But em I didn't then they said, oh we'll just take a wee bit away, but then but we'll try and take a lot of tissue away |

Jean was the only participant who did not report initial shock; she alluded to knowing that something had to be wrong given the series of repeated biopsies she had endured. It took four months for Jean to get a definitive diagnosis. During these months, Jean shared her recurrent nightmare; "I was in a butcher's shop, and they were slicing my body...you know so there was just a lump of meat, and they were just slicing it up, but it was, it was me they were slicing up and that, I had that for months" (#10:581-584). Although Jean did not report initial shock, there is little doubt that she had experienced an embodied response processed as she slept, evidenced in her macabre recurring nightmares.

ii) Coping with the Freedom and Responsibility of Choice. Although none of the participants wanted to have breast cancer, they did have to cope with the existential given that they had the freedom to choose how they dealt with it. All study participants elected to have treatment recommended to them by medical professionals. Not surprisingly, refusing treatment and ignoring the problem holds a high risk of secondary cancer spread and cancer-related death. However, participants had options related to post-mastectomy breast reconstruction; these choices were

constrained within limits of body mass index and were time sensitive. Beth shared how she felt pressured to decide on her surgery in a matter of days; in hindsight, she wished she had had more time to research her options more thoroughly. Debbie elected to have DIEPP Flap plastic surgery reconstruction because it sounded like a more natural procedure. Jean opted for the LD Flap reconstruction because she feared potential future implications related to having an implant. Both Debbie and Jean suffered psychologically partly in response to iatrogenic surgical trauma and because they experienced self-blame for their choices. Taking responsibility for choices can be linked with self-blame when the outcome of the option is negatively appraised. Blaming others is also a way of coping, but, interestingly, the participants in this study choose not to blame others for their treatment choices; instead, each managed by taking responsibility for their choices, even though this held implications of psychological suffering.

Debbie had donor site wound complications leaving her needing surgical dressings for three months and scars that she considers ugly. In addition, she harboured ambivalent feelings, wondering if her scars would be less noticeable if her wound had been managed differently, such as having help from community nurses rather than being left to see to her own wound care. Debbie coped by dwelling in these negative thoughts to come to terms and accept her changed body. It is only by sitting with her ambivalence that she could make sense of her experience and ease the burden of self-blame by sharing the responsibility for the outcome of her wound healing with others through a process of cognitive restructuring.

Jean is living with weakness in her arm and shoulder after opting for LD Flap surgery. Jean struggles with this disability as it limits her participation in former activities that she enjoyed, such as her drum circle hobby and working as a Reiki practitioner. Jean also has feelings of guilt related to self-blame for the outcome of her choices. Jean coped by ruminating in feelings of guilt related to self-blame for the outcome of her choices. This temperamentally based way of coping can be helpful in the shorter term. Still, it can be linked with psychopathologies such as depression and anxiety

when utilized as a long-term coping strategy. Eventually, Jean sought help from a mental health professional to enable her to come to terms with her treatment choices and resulting disabilities.

iii) Coping with Fear of Recurrence. The most prevalent long-term psychological repercussion for all participants is their fear of their disease returning. Fear of recurrence involves existential anxiety because it concerns living with an awareness of the possibility of death. It is a given of life that we all must die, yet people do not dwell on thoughts of the end of life. When faced with a mortal threat, such as a cancer diagnosis, death possibility becomes more real. Fear of recurrence is troubling because it is ambiguous, leaving participants sitting with uncertainty. The uncertainty of not knowing what the future holds feeds existential anxiety. Participants experienced fear of recurrence as thoughts kept in the back of the mind, describing how this fear moves into conscious awareness at times of increased stress, such as anticipating follow-up appointments and scan results. Debbie shared, "I still have my doubts now and then, I still have those times when I think oh shit, what if it comes back...I don't think it will ever, ever go away" (#4:454-457).

Similarly, Cindy shared that she was waiting for results from follow-up scans at the time of the interview; she said, "even though he's not, said he is not expecting anything, but I mean; obviously they can't guarantee anything, can they?" (#3: 37-38). Cindy copes by trying to focus on the positive yet simultaneously admits to worrying and dwelling in the negative too. Beth shared how she coped with waiting for her scan results by anticipating and accepting that she will have "a bit of a jelly-wobble" (#2:344-345), explaining that she will have a bad week trying not to worry about the results, followed by a sense of relief and ease at the words 'no evidence of disease' allowing her anxiety to fade, no longer the central focus of her attention. Beth appears to use a proactive coping style; she manages by anticipating that she will worry at certain times. But can reassure herself that her anxiety will only be a temporary state of being because she has learned from experience that it will resolve once the stress has passed.

### 4.2.2 Coping with an Altered Sense of Self

The sense of self is a central construct of existential thinking, seen as an ever-evolving non-fixed entity. Individuals create a coherent sense of self, a symbolic bridge linking the experiences of the inner private world, physical embodiment, and the external social world permitting them to survive and make sense out of life. Given that the self is ever-changing, paradoxically, people hold the opposite view, especially when stuck in repeated patterns of behaviour and thinking related to how they see themselves. Sense of self addresses identity concerns and the meanings attached to the different roles played in life. Table 9 (see p.83) shows the findings related to an altered sense of self from the analyses of participant interviews. All participants reported themes related to changed body image and identity. Nine of the ten participants described reduced self-confidence, while one described the opposite effect. Eight of the ten shared changes in worldview, while seven voiced the need for realignment of values and a focus on meaning.

| 'es Yes<br>'es Yes<br>'es Yes | s Yes   | s Ye    | s Ye                    | es<br>es                   | Yes<br>Yes<br>Yes  | Yes<br>Yes<br>Yes  | 10<br>10  |
|-------------------------------|---------|---------|-------------------------|----------------------------|--|--|---|
| 'es Yes                       |         |         |                         |                            |  |  | _   |
|                               | s Yes   | s Yes   | s N                     | 0                          | Voc  | Voc  | 0   |
|                               |         |         |                         | U                          | 163  | 162  | 9   |
| No Yes                        | s Yes   | s Yes   | s Ye                    | es                         | Yes  | No   | 8   |
| 'es Yes                       | s No    | yes     | s Ye                    | es                         | Yes  | No   | 6   |
| 'es No                        | yes Yes | s Yes   | s Ye                    | es                         | Yes  | No   | 6   |
| 5                             | 5       | 5       | 6                       | 5                          | 6  | 3  |   |
| 'e                            | s No    | s No Ye | s No Yes Yes<br>5 5 5 5 | s No Yes Yes Ye<br>5 5 5 6 | s         No         Yes         Yes         Yes           5         5         5         6         5 | s         No         Yes         Yes         Yes         Yes           5         5         5         6         5         6 | s         No         Yes         Yes         Yes         Yes         No           5         5         5         6         5         6         3 |

Allison struggled to come to terms with the changes in her body image after surgery. She disclosed feelings of disgust related to her reconstructed breast; "I think body image femininity, lack of feeling, it's partly disgust at what I look like" (#9:423). Disgust is a robust descriptor connected to her loss of femininity, suggesting a need to cope with body shame. The implications of these shameful feelings have exacerbated her lowered libido resulting in avoiding sex with her partner.

Allison explains, "I have just gone completely off the boil, and it's because I don't feel feminine, I feel

mutilated" (#1:113). She continued, "I can't bear the thought of being touched, and I'm just, I do this, I freeze and just think I can't, I can't, and how can anybody find this attractive?" (#1:428-429). Allison copes with body shame by avoiding intimate contact with her husband. Allison recognizes how her cancer diagnosis and surgery impacted her global worldview "it's all over my life this stuff" (#1:2005). Specifically, Allison worries about reduced self-confidence; "I've lost my confidence; things I'd take in my stride I now have to really gear myself up to do" (#1:127). Contrasting and comparing herself before and after her cancer diagnosis, she gives the impression that her life was easier before and now everything takes more effort. Worrying and ruminating in negative thoughts was the catalyst for Allison's recognition of her need for professional help to navigate this altered state of being. Seeking help from others by engaging in psychotherapy and Reiki energy healing helped Allison come to terms with her perceived problems.

Beth shared her experience of disconnecting from her sense of self during treatment. Her words illustrate how she felt exposed and vulnerable, as she metaphorically handed her body over to men to fix it. The act of taking her top off held new meaning for Beth when she disconnected from her body. Viewing herself as an object, Beth was able to become blasé when exposing her naked body to others:

"I mean I've taken my top off for more men than... I've had men, my surgeon, my radiologist, and then the guy doing the aspirations and I was forever taking my top off and you became blasé, ... cos to deal with it I had to disengage from my body that it was theirs and they were going to fix this machine called body and they can do what they like with it as long as they get it better and sort it, and then you are left with this new thing called body and you sort of don't own it; everyone else has owned it" (#2:281-286).

Engaging in massage therapy helped Beth to cope with her feelings of disconnection. Massage empowered her to reclaim her body that she believed others had owned. Beth said, "but then you

need to take ownership of your own body again and that's where complementary therapies helped because I could be feminine again...and the massage being a touch therapy helped me get used to it" (#2:282-287). This finding is important because it adds to the understanding of unintentional trauma that can occur during medical procedures. Beth coped with her trauma by separating her feminine sense of self from her physical embodiment. Dissociation could be interpreted as a way of coping to tolerate a challenging experience. Later, Beth coped with the disconnection from her body by engaging in therapeutic touch therapies, a problem-solving way to reconnect to her embodied self. This finding raises broader questions about the sexual objectification of women's bodies in Western culture, specifically what it means for women to expose their breasts. In a multicultural society like the UK, this finding has significant ramifications. I wonder about vulnerabilities for women related to cultural variance and for women who have personal histories of sexual abuse.

Cindy struggled to adjust to her changed physical appearance related to the effects of her treatment; "Because you know, I had long, Mediterranean hair, you know, my skin was good, and I just, I just don't feel attractive at all. I, physically I don't (#3:163). Although she looked different and no longer felt like an attractive woman, Cindy faced a paradox, she was still the same person inside: "I got angry. This is me. You know. I haven't got hair, I haven't got... you know, all these things are going on, but I am me" (#3:213). Cindy coped in the short term by expressing her emotions to reduce tension. Cindy shared how her world view changed after cancer observing "I am not how I was before. My outlook has changed" (#1:247). A changed outlook points to how Cindy coped by reviewing and adjusted her values. For example, Cindy decided to give up work so that she could spend more time with her grandchild, an example of coping by realigning her priorities. These findings hold important implications for working with a sense of self in psychotherapy practice. Using an existential approach to explore the dilemma from different dimensions, in this case, the physical and personal worldviews, can uncover new meaning and facilitate adjustment to change.

Since her breast cancer surgery, Debbie also has an altered body image. She does not like the look of her scars on her abdomen nor her breast and nipple reconstruction. This altered body

image is particularly troubling for Debbie, as a naturist. Debbie shared her concern that when she attends naturist events, others will see her scarred body and know that she has had breast cancer. To cope with this dilemma, Debbie plans to have a tattoo across her chest and abdomen, "I have decided to have my own tattoo because I want to cover it up because it looks so ugly" (#4:286). Taking action to improve her body image with a tattoo is a problem-solving coping strategy that gives Debbie a sense of control.

Weight gain altered Emma's self-image. She has felt depressed about how she looks and struggles with self-loathing because she does not consider herself a vain person (#5:882). Emma coped with her ambiguous feelings by looking on the positive, a way of reframing unhelpful views, sharing her new mantra, "I'm fat, but I'm alive". However, in the next breath, Emma also admitted, "But I don't like that mantra, not at all" (#5:918). These findings shine a light on the complexity of coping, how, on the one hand, positive thinking reduced tension temporarily, but it did not alleviate deeper-rooted feelings of shame.

Fay reflected on her changed relationship with her body since her breast cancer diagnosis and subsequent treatment:

"I am more of a fan of it, and I am more in tune with it... I think that if I had been more in tune with my body, I might have noticed things a bit sooner. Um... and... um. You know, I have a history of, of being overweight, and, and at the moment I am in the process of losing it and I've... doing a lot more exercise because I do respect the fact that it got through chemo in one piece" (#6:284-287).

Fay speaks about her body as an object, almost as if it is a separate entity ('fan of it'), yet she used the word 'I', owning her part in being overweight. There is also a hint of self-blame for neglecting to notice her body or be attuned with it. Having breast cancer, difficult as this was, provided an opportunity for Fay to discover new meaning in her relationship with her embodied self, being more respectful of her body that coped with the rigors of treatment and emerged anew.

Mastectomy surgery impacted Gail's body image and her awareness of her feminine self. Gail revealed how she has become more self-conscious and limited in her choices of clothing due to her need for a breast prosthetic. She thinks more now than she previously did about how her clothing fits, "if I am going to have a top, you know, it can't show too much down the side, it can't be too low, you know" (#7:148). Gail wonders, "what can I, you know, wear? Uh, and, and that's become a bit of a thing, it's one of these sorts of reminders that, woman is sort of bound up with the breast, thing" (#7:149-150). The phrase 'a bit of a thing' suggests a concern, a level of discomfort Gail has related to being reminded of her cancer, especially when getting dressed. She has become acutely aware of how the world sees breasts as sexualized objects. The significance of this finding illustrates the impact on Gail's sense of self as a woman, and she must cope and adjust to what it means to be a changed woman with only one breast. Gail values physical fitness: efforts to cope with her altered sense of self influenced her choice to swim rather than run, rationalizing "if I am in the water, I'm ok because your... I'm hidden (laughs)" (#7:168). Hiding points to Gail's desire to control how others might see her and avoid feeling shame in her imaged view that they would judge her negatively. The coping style she uses is both problem-solving and avoidant. Gail avoids the embarrassment she anticipates while being seen by others by adapting her behaviour, using the water as a shield, and simultaneously meeting her exercise goals.

Heather was in the process of intentionally changing her body image by losing a significant amount of weight prior to being diagnosed with primary occult breast cancer. During her cancer treatment she regained some of this weight, leaving her "desperate to get back and lose that again" (#8:335). Surviving cancer impacted Heather's worldview in positive ways. She reported a change in her attitude; "I'm a bit like seize the day now, you know" (#8:806) sharing her newfound passion for running. Unlike others who reported a loss of self- confidence, Heather shared how her confidence soared, emerging from shyness and reluctance to try new things to a newfound passion for living. Freed from former meanings attached to failing or not being good enough, Heather now focuses on living her life to the full; "Let's give it a go, (laughs) what's the worst that can happen?" (#8:810).

Heather copes by focusing on the positive, seeking relaxing diversions and humour. She also infuses ordinary events such as running with meaning and finds benefits in her cancer experience, such as gratitude that she is alive.

Irene, like Heather, shared a similar experience of letting go of sedimented ways of being and self-doubt. Before having cancer Irene stressed about her work performance, worrying about not being good enough and catastrophizing about the outcome if she were to make a mistake. Now Irene holds the view "well, do what you can while you are there and move on" (#9:413-415). Irene coped by positively reframing her negative thoughts, and realigning her priorities, she recognized that she needed to conserve her energy for more important things like spending time with her family. Finding new meaning helped Irene cope with her changed worldview. Irene was able to adjust to how her life will never be the same again; "It doesn't go back to what it was, you are constantly living with your changed body, with the side effects of whatever continuing drug you are having" (#9:647-648).

Jean struggled with a crisis in identity after her surgery as she tried to understand her felt sense of disconnection between her mind and body.

"I don't recognize myself. Uh. In, in, um... I can remember when I came home after all the surgery, I had said ... I'm a different person. And I think somethings happened in the operation because I'm not the same person...it was like I was an alien. You know. I wasn't. I didn't recognize any part of, kind of, in my, in my head or physically, um, and emotionally. I did not connect with any of it and it's still a bit like that" (#10:448-454).

Jean was particularly upset about this sense of disconnection because her identity and self-concept was anchored in being a holistic practitioner, doing Sachem Reiki, and work with crystals. In addition, Jean meditated and ran groups to teach others mindfulness mediation prior to her breast cancer diagnosis. Her surgery experience left Jean facing loss of meaning in all the healing practices that had kept her grounded in the past. Taken out of context, Jeans words could sound like an example of a person having a psychotic break from reality; but for Jean the meaning is about being

greatly disappointed in the failure of her wellbeing practices that did not fulfil her magical thinking that they would prevent her from getting cancer. Jean became depressed in response to her belief that "all of that had let me down, so I really didn't have that to help cope with, in a way. So, I think it was just a.... I kind of shut down" (#10:74). Jean coped with a crisis of uncertainty related to her values by withdrawing into a low mood, wondering how she could carry on while feeling let down by the things she relied upon for comfort and security. However, despite her low mood Jean also coped by reaching out to a cancer charity helpline and followed through with the recommended referral to meet with a clinical psychologist (#10: 350).

### 4.2.3 Coping in the Personal Dimension Summary of Findings

The impact of primary breast cancer in the personal dimension for participants in the study can be summarized as initial shock followed by fear and uncertainty as the participants adjusted to the unfamiliar physical world of hospital and cancer treatment. They faced feelings of repulsion and disgust as they witnessed changes to their bodies and had to tolerate foreign objects such as surgical wounds, drains and intravenous lines. They faced paradox and ambiguity around meaning while making sense of experiences, for example Allison viewed her surgery both as a traumatic event but also one that saved her life (#1:104). Her feelings of shame and disgust about her mutilated breast sit alongside feelings of gratitude that she still has a breast. Allison wants to stop feeling ashamed and disgusted viewing this as unhelpful and impeding her mental health, so coping meant looking after her mental health by engaging in psychotherapy (#1:300). Even though Allison has chosen to pay for private psychotherapy she also holds feelings of resentment that this type of support was not available to her within the health service as part of her ongoing treatment plan.

Study participants reported multiple examples of how their diagnosis of primary breast cancer impacted upon them psychologically. They faced the existential givens of freedom and responsibility for choice and coped with fears of recurrence of disease. In addition, they coped with an altered sense of self. Coping strategies were revealed, such as using of anger as a motivating

factor, the benefits of cathartic release of emotions, and processes of cognitive restructuring where explicated by choosing to focus on positive rather than negative aspects of experience. Participants utilized avoidance strategies for different reasons. For example, Fay avoided a woman who wanted to tell her negative stories about others with breast cancer. Others avoided being left alone, ensuring that they kept family and friends nearby, to cope with feelings of fear they experienced when alone with time to ruminate and worry. Coping within the personal dimension illustrates multiple challenges with wide reaching implications for mental wellbeing. The third super-ordinate theme addresses findings related to the interpersonal world of participants and how they coped in the social dimension of life.

# 4.3 Super-ordinate Theme 3: Coping in the Social Dimension

The interpersonal nature of being is the existential given encountered in the social dimension. People always exist in relation to others; this is both unavoidable and essential for the co-creation of shared values that give life meaning and facilitates the maintenance of a coherent sense of self. The biggest threat to wellbeing in the social dimension is that of rejection; this can give rise to existential anxiety in the form of isolation. All participants experienced changes in their relationships; some grew and strengthened, becoming more meaningful, whilst others were lost. The polarity between loss and gain within the relational world produced coping skills by experiencing meaning in care. Three sub-themes emerged; the first was finding meaning in care, including caring for others, being cared for, and finding meaning in care within medical relationships. The second showed how participants experienced meaning related to work (see Table 10, p.91). Findings shone a light on the complexities of work and how it interconnects as a social activity, a physical concern, and how work-life influence's identity and values. The third pertains to coping with ambiguity while sitting in the gaze of others; what it was like to cope with feeling pitied, managing feelings of shame and guilt and the dichotomy between how participants viewed themselves compared to how they thought others saw them.

| Sub-themes Findings in the Social Dimension | #1 Allison | #2 Beth | #3 Cindy | #4 Debbie | #5 Emma | #6 Fay | #7 Gail | #8 Heather | #9 Irene | #10 Jean | Count Yes |
|---|------------|---------|----------|-----------|---------|--------|---------|------------|----------|----------|-----------|
| Meaning in Care                             |            |         |          |           |         |        |         |            |          |          |           |
| i) Being cared for by others                | Yes        | Yes     | Yes      | Yes       | Yes     | Yes    | Yes     | Yes        | Yes      | Yes      | 10        |
| ii) Caring for others                       | Yes        | Yes     | Yes      | Yes       | Yes     | Yes    | Yes     | Yes        | Yes      | Yes      | 10        |
| iii) Meaning in Medical Care                | Yes        | Yes     | Yes      | Yes       | Yes     | Yes    | Yes     | Yes        | Yes      | Yes      | 10        |
| Meaning of Work                             |            |         |          |           |         |        |         |            |          |          |           |
| i) Changed values related to work           | Yes        | Yes     | Yes      | Yes       | Yes     | Yes    | Yes     | Yes        | Yes      | Yes      | 10        |
| ii) Work a source of self-concept           | Yes        | Yes     | No       | No        | Yes     | Yes    | Yes     | Yes        | Yes      | Yes      | 8         |
| iii) Work as a physical concern             | Yes        | Yes     | No       | Yes       | Yes     | No     | No      | No         | Yes      | Yes      | 6         |
| Ambiguity in the Gaze of Others             |            |         |          |           |         |        |         |            |          |          | 10        |
| i) Coping with Pity                         | Yes        | Yes     | Yes      | Yes       | Yes     | Yes    | Yes     | Yes        | No       | Yes      | 9         |
| ii) Paradoxical views self                  | Yes        | Yes     | Yes      | Yes       | Yes     | Yes    | Yes     | Yes        | Yes      | Yes      | 10        |
| iii) Guilt and Shame                        | Yes        | No      | Yes      | Yes       | Yes     | Yes    | Yes     | No         | No       | Yes      | 7         |

# 4.3.1 Finding Meaning in Care

All participants described their unique understandings of meaning within their relationships. They shared experiences of personally caring for others and of being cared for by partners, family, and friends, during their illnesses. Paradoxically, participants also faced breakdown and loss of essential bonds, leaving them to cope with feelings of rejection and abandonment. As Allison put it, "you find out who your friends are" (#1:241). Medical relationships held special meaning; the findings showed how participants coped by trusting strangers; allowing them intimate access to their bodies to address matters of life and death. Participants coped by ceding control while taking a leap of faith, trusting the process, and hoping that the abilities of others would restore them to wellbeing.

i) Coping by Finding Meaning in Being Cared For. Participants experienced ironic differences between wanting to be cared about and needing to be cared for. The participants held a shared cultural ideal of independently coping alone, having a strong sense of personal agency and self-efficacy that was challenged by the reality of illness. Participants faced new meanings as they let go of their agency and relied upon others.

Jean particularly struggled with the idea of needing help. As a health care professional, she identified with the belief that she ought to be caring for others, not being cared for herself. Her

personal history of disrupted attachment in childhood complicated matters and reinforced her sedimented beliefs further. Jean wasn't used to, nor did she expect to be cared for by other people. As an infant Jean's parents left her in the care of her grandparents, who are now deceased. Jean remains estranged from her birth parents (#10:525). As an adult Jean's intimate partnership ended, leaving her to raise their four children singlehandedly (#10:519). When Jean was diagnosed with breast cancer, she coped by isolating herself from her friends because she could not tolerate their attention, well-meaning as it was. To manage her interpersonal relationships and avoid speaking with people face to face, she set up a WhatsApp chat group online and posted updates for her friends and family during her cancer journey (#10:75-77). Jean coped with her need for others to care about her by controlling how she communicated with them; she wanted to matter to them, but she could not tolerate witnessing their sadness and fear. Jean said, "I did in the beginning, speak to friends about it, but they would all be sitting and crying, and I would get really, really angry about that... (starting to cry) you know, why me? Why are you crying? It's not happening to you. So, I can ah, so there was a few friendships, kinda went by the wayside" (#10:78-80). This example shows how Jean coped with behavioural disengagement to avoid her negative emotions, such as feelings of anger.

Jean was not the only participant who experienced loss in relationships. Irene had two major losses to cope with in addition to her cancer diagnosis. Irene asked her counsellor, "how rubbish does your life have to be when you're having breast cancer is third on the list?" (#9:59). Given her circumstances, this statement is understandable; Irene's marriage had deteriorated over several years, but her husband finally left the family home during her cancer treatment. Around the same time Irene's mother died. This example is helpful because it reminds clinicians that people do not exist in one dimension, nor do they experience life in a linear fashion. Concurrent losses of key relationships challenged Irene while her health was threatened. Irene still had to function as a mother of two teenaged children and because she was historically the primary breadwinner of the household, she needed to work. Irene used a variety of coping strategies in addition to the problem-

solving style of reaching out for professional psychotherapy. For example, Irene coped by accepting help from her sisters, friends, and children, such as taking transport offers to and from her chemotherapy appointments. Before being diagnosed with cancer, Irene welcomed a new puppy into her family, describing this new addition as a blessing and a curse. Irene has bonded with her dog and credits this canine relationship with keeping her sane and getting her motivated to go out for walks. This example demonstrates how Irene coped by seeking relaxing diversions. Walking the dog gave her time for herself to contemplate the world while getting some exercise.

Irene also coped by seeking social support by attending breast cancer support groups which she values and highly recommends. Irene found the groups helpful; she related to others who shared her insider knowledge about breast cancer, "you both know what you are going through. Whereas someone who hasn't been through it... probably just thinks, oh she felt a bit ill" (#9:591) and "You don't know, unless you've been there" (#9:595). Irene benefitted from attending a psychoeducational group that addressed issues such as fear of recurrence and living with the side effects of ongoing hormone therapies; "it's a voluntary basis, and you er... and I think women should be... actively encouraged to go" (#9:635). This type of coping by engaging in psychoeducational and peer support is a problem-solving style.

Allison reflected on the meaning of the care shown to her by her four daughters and more importantly her husband, "who loves me to bits, who puts up with my awful, the mess that I am now" (#1:321). Unconditional love from her husband, who loves and accepts her as she is, has been instrumental, enabling Allison to cope and come to terms with her body shame and loss of libido.

Primary occult breast cancer is very rare, leaving Heather yearning to find someone who shared her diagnosis. Heather wished she could meet someone to compare experiences to help her understand how others coped so that she might also cope with the ambiguity of her disease.

Heather explained how she actively coped by joining the online cancer support community on social media platforms such as Twitter and Facebook and how this has been a meaningful experience.

Heather has been inspired by the women and the stories they share (#8:752-753). Through social

media Heather connected with a survivor like her; "she said oh, that's what I had, and I was like, gosh, yes, so we've sort of made contact... she just lives up somewhere, north somewhere, and so we just chat on Facebook... and she has given me lots of tips and everything, and you just think, oh wow" (#8:1024-1025). Advances in internet technology and social media provide a lifeline to help women like Heather and many others who might not have physical access to in person peer support. Coping by seeking social support for a stressful event such as cancer is both a problem solving and meaning-focused coping style, particularly highlighting the importance of finding meaning in relationships to cope with feelings of isolation.

Fay also found peer support groups helpful, however she shared a cautionary tale of her experience of other people with cancer whom she perceived as "spectacularly annoying" (#6:393-394). Fay had an acquaintance who was diagnosed with breast cancer around the same time she was. Fay felt annoyed as the woman compared her situation to Fays, deeming Fay as far more seriously ill. Fay reported coping with this by dwelling in negative feelings, expressing her anger at being objectified, used as an example to aide another woman cope with her cancer. Fay used avoidant coping behaviour, choosing not to engage with people who upset her.

Fay's partner Mike was also diagnosed with cancer during her cancer treatment. She spoke of how they became closer and how their shared experience "made the journey, I would say a bit easier" (#6:363). Together they coped by sharing the burden of navigating the health system and looking out for one another. As a result, they emerged with a strengthened relationship and celebrated by getting married. This serves as a dual example of finding meaning in being cared for and finding meaning in caring for others.

ii) Coping by Finding Meaning in Caring for Others. Jean's experiences of loss during her life shaped the meaning of the need she has to care for her adult children. They are now young adults aged between of twenty-two and thirty-two, but Jean worries about the impact her death might have on them. She disclosed how close and how small her family is, stating "it's just us" (#10:526), meaning herself and her four children, identifying as both mother and father in the family unit. Jean

shared new awareness of feeling greater responsibility to fight cancer and survive, not only for herself but because she cares and wants to be alive for the sake of her children. The maternal bond helps Jean to make sense of why her life matters.

Debbie derives meaning from nurturing others. Even during her chemotherapy treatment, she continued to cook and host gatherings for family and friends. Cooking was a way of coping for Debbie, it was a link to her sense of self, supporting her identity as the matriarch of her family. Cooking can be viewed as a relaxing diversion that allowed her to spend time with family and friends. Caring for others is an important part of her value system. Debbie continues to attend peer support groups and is willing to share her experiences because she wants to give back, the same way others helped her by paying it forward. Activities like this are examples of coping by taking social action.

Allison, a former social worker, and self-confessed "empath" (#1:211) holds an opposing view to peer support groups. Allison avoided support groups because she feared that she would be overwhelmed by the pain of others, "I'm always the one who gets Margaret from Hove crying on her shoulder, you know, I attract other people in pain, and I thought, I can't deal with other people who are in pain at the minute, I have got to deal with my own stuff" (#1:106-108). Allison's history of finding herself overloaded by other people who often took advantage of her good nature; "I used to be a sponge for absolutely everybody and now I am not" (#1:355-356) left her wanting to avoid needy people. Allison coped by avoiding situations and people she appraised as 'needy' by changing her behaviour, learning to set personal boundaries, and saying no. Since having cancer Allison has realigned her priorities, instead of caring and doing for others, she has set new boundaries to enable her to focus on caring for herself first. However, Allison also has a new awareness of the need to reach out and reconnect with special people, those friends and family members she considers important, whom she has not seen in a long time (#1:360-361). Allison's case illustrates the need for balance between being with others whilst maintaining a sense of self.

iii) Coping by Finding Meaning in Medical Relationships. Having trust in the medical team was reported by all participants. Jean shared how she choose her consultant since she was familiar with her and trusted her (#10:113-114). Familiarity with the consultant helped Jean cope with the uncertainty surrounding her. Irene talked about feeling comforted by the way her team set out her treatment plan, trusting that if she went along with it she would get better (#9:51-52). Irene coped by focusing on solving the problem and ceded control of her health to others. Heather saw her relationship her medical team as an integral part of her coping strategy "professionals you can trust basically, who you know are doing their absolute best to try to sort you out" (#8: 278-279). Heather particularly appreciated her relationship with the breast care nurses who were available to explain things and reassure her when reached out for support (#8:275-277). Beth echoed this sentiment, sharing how her relationship with her surgeon helped her to cope. Beth felt safe with him because he took charge and explained things to her clearly; "this is what you've got, this is what you're gonna take, these are your options and I'll look after you, and I can do A,B or C have a think about it" (#2:70-71) and this helped Beth trust him because he made her feel like she mattered (#2:116). Fay shared how she felt at ease communicating with her medical team "If there was anything worrying me, I addressed it immediately with my team" (#6:26) implying a collaborative working relationship. Cindy shared how she felt reassured by the breast care nurses who helped her to cope by giving. her hope, "just knowing that they were there and would send that word of encouragement and it would keep me going (#3:86-87). Allison experienced a sense of loss of control when facing breast cancer treatment. Allison decided to cope with this distress by acceptance, realizing, "I've just got to let these people deal with it, they know what they are doing". Allison coped by placing her trust in the medical system; this purposeful action relieved her of the burden of responsibility, helping her to cope and regain a sense of personal agency.

Debbie also coped by trusting the medical team to guide her during her treatment, regarding her surgeon she said, "I thought that he knew everything at the time. Obviously, I had all my faith in him because he was going to save my life... um... so, you know, I just listened to

everything he said (#4:653-654). Debbie illustrates here the level of power that is held by medical professionals. In hindsight Debbie holds more ambivalent feelings. She reflected on her belief that because her surgeon was male, who does not have breasts, breast cancer, nor undergone such radical surgery himself, that he has no idea what the surgery and recovery entails for women (#4:656-657). This type of coping is an example of ruminating and dwelling in negative thoughts. Debbie also coped by expressing regret, as she wished that she had the opportunity to speak with other women who had similar breast reconstruction to hear insider knowledge before making her decision. Although Debbie has some regrets, she holds much gratitude for the health service in general, "I'm not going to complain at all. They did a fantastic job, and you know the NHS are bloody brilliant" (#4:760). Praising the health service is an example of coping by accepting her situation using cognitive restructuring or positive reframing.

### 4.3.2 Meaning of Work

All participants experienced change in meaning related to their work lives. Each reflected on how their cancer diagnosis, impacted on their values, sense of self-concept and how choices about work were governed by financial and economic stability.

i) Coping by Finding Meaning in Work. Allison describes herself as the sort of person who wakes up in the morning happy to go to work (#1:159). Working as an archaeologist, Allison benefits not only from the mental stimulation but also from the comradery, enjoying the company of her colleagues. Her breast cancer has left her with a slight weakness in her affected arm however Allison takes this in her stride rationalizing that it is only a year since her surgery and believes she is still healing. Allison is grateful that she likes her work and derives satisfaction from it, her work has helped her cope with maintaining her professional sense of self.

Beth is a holistic therapist, providing therapeutic massage for people undergoing treatment in a cancer centre. Her work has taken on new meaning since her own cancer experience, sharing how her medical team inspired her to be the best she could be in her work with cancer patients

(#2:234). Beth is particularly interested in helping women work through sexual intimacy challenges after treatment using massage, "I'd love ladies to know that you can still have a lot of intimacy with massage" (#2:310) continuing, "it's a shame they don't run massage courses for ladies to be able to learn a way to be intimate with their husbands, there you go I've found my new career (hearty laughing)" (#2:319). Beth communicates a sense of legacy, an honest desire to give back and try to improve life for women after breast cancer treatment. This is an example of coping by taking social action.

ii) Coping by Finding Work Meaningless. Three study participants reported meaninglessness in work after breast cancer. Cindy, Debbie, and Gail coped with their adjustment to a cancer diagnosis by stepping away from work as they realigned their priorities about what mattered to them after facing serious illness. Cindy wanted to spend more time with her grandchild. Debbie took redundancy and explored the possibility of fostering young mothers with babies; a more meaningful activity for Debbie and better fit with her preference of caring for others. Gail retired to spend time traveling and enjoying life with her husband. Meaning-focused coping styles like realigning priorities gave the participants an opportunity to reflect on their work-life balance and decide what mattered most to them.

temporarily step back from working during chemotherapy. Fay was self-employed and was able to take the decision at the start to have a sabbatical with financial assistance provided by her mother. Heather worked part-time as a college lecturer, but as her treatment progressed and symptoms worsened, she could not cope with her workload and had to resign. Irene had a similar experience, she worked flexible hours until she was unable to manage, but instead of resigning her employer extended her paid sick leave, this was vital for Irene providing her with the financial stability to cope with the socioeconomic pressures as a newly divorced single parent.

Emma was fully supported financially during sick leave with benefits from her duties as a police officer. Being a police officer for Emma is not just a job, she considers it a calling, and it is part

of her identity. She considers colleagues to be her 'police family' (#5:192), and this bond helped her to cope, showing how meaning is infused in her work life balance. However, since completing her treatment Emma finds herself in a crisis of meaninglessness. Emma struggles to return to her duties, doubting her ability to return to the stress of front-line policing, and questions her self-worth related to loss of physical fitness needed to do her job. Emma copes with her fears using worry, rumination and self-blame. Taking a break from her work has afforded Emma time to recuperate physically and to adjust to her existential awakening using cognitive reappraisal and meaning-focused strategies such as realigning priorities to discover what matters most to her now.

Jean, like Emma, also has had to face physical limits, potentially impeding her ability to practice massage and energy healing. Although Jean is fully employed as an occupational therapist, she struggles with feeling disconnected from the important meaning she derived from her extracurricular work as a holistic healer. Jean copes with her feelings of sadness and loss in two ways; she reduces tension by expressing her emotions and holds on to hope by wishful thinking, that in the future she will eventually be well enough to return to her complementary healing practices.

These findings highlight the interrelated meanings work can hold and how it can impact on coping ability. Work is not just something people do; it is much more. Work offers connection to a sense of self in the personal dimension, a means to survive financially in the physical dimension, a way to relate and feel connected to others in the social dimension and in the spiritual dimension, work can be interpreted as a meaningful way to leave a legacy, or at the same time it might be interpreted as a time thief, a distraction from what really matters.

# 4.3.3 Coping with Ambiguity Sitting in the Gaze of Others

Findings about coping in the social dimension uncovered a need to cope with ambiguity in relationships. Participants had to tolerate and make sense of opposing views of themselves; on the one hand they had their personal view of how they felt and looked while simultaneously experiencing a different view reflected from others. Dealing with pity brought up feelings related to

anger, while facing paradoxical views of self, invoked feelings of guilt and shame. It is a given that we are always seen by others, and it could be argued that we need to be seen or noticed to exist in the minds of others.

Jean felt embarrassed when her friends insisted on helping her. She explained, "everybody was wanting to help me all the time and I found that embarrassing. I'll carry your drum for you, I'll get this for you, I'll pick you up, I'll take you here. You sit there... and just thought I'm not an invalid. You know. But. They see me as an invalid" (#10:471-473). Being seen as an invalid left Jean to cope with feelings of shame; she coped by focusing on the negative meaning she associated with being seen as an invalid, and by ruminating in anger to release her tension. Jean sees herself as a strong and independent woman and she has difficulty tolerating other people seeing her as an invalid. Synonyms for the word invalid are unacceptable, worthless, and unsound; no surprise Jean felt shame and anger in response to a word infused with judgement. Jean's perception of acts intended as care and kindness, are important reminders of the difficulties people have communicating and how easy it is to be misunderstood. Jean needed to feel autonomous, but instead ended up sitting in shame which resulted in her use of an avoidant coping style, isolating herself from her friends.

Gail shared her experience of feeling down when people around her focused on the positive and minimized the seriousness of her illness with comments like "oh you'll be fine because you're fit and you're healthy and you run half marathons and... you know, everything is tickety boo" (#7:312-313). Gail had to cope with not feeling OK in herself and feeling invalidated by others, particularly her parents who held the view; "oh you'll be alright, you know. Um. Everything will be alright. You know, just, just get on with it, you're, you're fine" (#7:320). To cope, Gail occasionally vented her feelings of anger and fear with her husband, but mostly kept to herself not letting others know how she felt. Gail also experienced feelings of shame and guilt as she imagined what others would think of her; "I guess I didn't want to seem like I was a err... a failure, I guess. That I wasn't you know, strong. And because I had come from the medical profession that I didn't, understand this and I knew... what to do" (#7:318-319). Feelings of guilt and shame for Gail are rooted in her need to be

seen as strong, capable, and successful. Psychotherapy could allow Gail to dispel the myth that because she had been a nurse, she should have known how to cope with breast cancer and manage everything by herself. It could also allow space for Gail to explore what it means to be strong or weak and what it means to succeed or fail.

Debbie shared her experience of the end of her cancer treatment and how she and her husband held opposing viewpoints. Her husband took the view that she no longer had cancer and that she could return to work with him, and life would go back to normal. Debbie believes that "he just wanted to blank it, like it didn't happen" (#4:236). However, this type of denial was not possible for Debbie because she knew that her life would never be the same again. Debbie coped with this conflict by assertively explaining her point of view to her husband; sharing how work had changed meaning for her and how she had realigned her priorities and no longer wanted to continue to work in the family business.

Heather shared her experience of coping while living with a PICC line during chemotherapy. She hated having it in her arm, seeing it as a constant reminder of her cancer. It got in the way, interfering with basic activities like bathing and caused her much distress. Heather coped by focusing on the negative, blaming the PICC line for reminding her of her fears and worries about her cancer. Yet others tried to keep positive and told her she was managing brilliantly. Heather found this ambiguous because she did not feel brilliant sitting with the inconsistency between her lived experience and how she was perceived by others. Heather cited another example of this type of paradox when she made the decision to stop her chemotherapy treatment early. Heather argued her position with the oncologist; "You might look at me and think she is absolutely fine, but inside I am just crumpling up and I can't do it" (#8:937). Taking the stand to stop treatment early was based on Heathers felt sense that her body had had enough and might not survive another round of chemotherapy drugs and side effects. Heather coped by listening to her body rather than allowing the perception of others to guide her choices; this type of coping is an example of self-advocacy by taking action to solve the problem as she appraised it.

### 4.3.4 Summary of Findings in the Social Dimension

The social dimension findings show how participants coped with living with breast cancer in their wider interpersonal relationships, pointing to the meaning that is attached to the concept of care; caring for others, being cared about by others and the trust participants placed in medical teams. Coping in the interpersonal realm also showed how participants found meaning in work and how breast cancer impacted on their working lives. Participants also experienced ambiguity and had to cope with complex feelings as they navigated their relationships with a new awareness of the difference between how they viewed themselves compared to how they thought other people saw them. Participants used a variety of ways of coping to manage feelings of ambiguity including strategies like dwelling in the negative, worrying and expressing emotion to reduce tension.

However, the most prevalent way of coping within the social world was the use of meaning focused coping, evident across all participant interviews and was also seen in the next superordinate theme of coping in the spiritual dimension.

# 4.4 Super-ordinate Theme 4: Search for Meaning in the Spiritual Dimension

The spiritual dimension includes religiosity and spiritual transcendence; however, it is not limited to these concepts. The existential view of the spiritual is open to a broader interpretation, that includes a search for meaning in relation to life experiences. Meaning shapes how individuals situate themselves in the wider world in relation to their values, beliefs, and sense of purpose. The diagnosis and treatment for primary breast cancer ignited existential concerns about death, isolation, freedom, and meaninglessness; in the face of which participants reevaluated their lives. It is this search for new meaning that is at the root of coping in the spiritual dimension. The findings are presented in three subthemes; the first is spiritual beliefs and coping with existential concerns, the second reports on the role of complementary therapies in spiritual support and the third attends to meaning focused coping.

#### 4.4.1 Spiritual Beliefs and Coping with Existential Concerns

None of the study participants identified as members of any organized religion. However, each held secular views sharing what spirituality meant to them and how they coped with existential concerns. Gail shared her that she was not religious but held the following spiritual understanding: "I believe in nature and the world and all being part of one thing, I guess that is Buddhism but no I am not a Buddhist" (421-423). During her cancer experience Gail turned to the local Buddhist Centre where she found a sense of peace engaging in communal online meditation practices. These new meditation skills helped her to ground herself during periods of anxiety, particularly at night, "trying to sort of stop myself from over thinking and... stopping the chattering monkey that sits, sits here somewhere in the brain, I think. Ha ha (laughs). Calming him down" (#7:410-412). Although Gail does not identify as a Buddhist, the meditation practices she learned have helped her cope with her existential anxiety.

Allison does not believe in God, but she holds ideas of spirituality related to "a collective kind of energy" (#1:332) explaining, "we are all energy there's good and bad energy as we all know and I just kind of feel I am tapping into a lot of good energy now and I've got some really good people who are helping me" (#1:335-336). In addition, Allison clarified her belief that it was a "female flow of energy" (#1:339) experienced during Reiki and psychotherapy that helped her to cope and manage feelings of disconnection from her body, by becoming more connected to her feminine self and the earth (#1:341).

Debbie identified as atheist, not religious in any way, and disclosed that she had considered her death and what she wanted to happen to her body after she died, long before ever facing cancer. Debbie shared an account of her ideal funeral; she did not want a religious ceremony and was equally content to either be buried in a natural site, such as a woodland, or be cremated. If cremated, Debbie wanted her ashes scattered in a special place that held meaning for her and her family. Although Debbie had these ideas before diagnosis, she still experienced death anxiety while

undergoing her treatment. Debbie thought about all the things she still wanted to do in her life and simultaneously ruminated about the details of her funeral, leaving her feeling anxious and uncertain. Her experience resulted in an existential awakening, "I don't know if I've got a year, 5 years, 10 years. I just don't know, so I've just got to say yes to everything, and make the most of it [life]while I am still here, so it's made me stronger" (#4:476-477). As a result, Debbie feels stronger in herself. She copes by adopting a new attitude to embrace every moment and finding the positive in her illness; this is an example of coping by engaging in benefit finding.

Emma shared her view that although she was not drawn to religion or to "find God" she did believe "that there is something" (#5:691). Emma wished that she had a stronger sense of faith and shared her envy of those who do, reasoning; "I think if you've got a faith, you've got more afterwards, and that may be helpful. But I'm not so sure" (#5:695). Emma is uncertain about her spiritual self. She sits with conflicting viewpoints; her words 'you've got more afterwards', hint at the possibility of coping by engaging in wishful thinking, hoping to defy death by holding a belief in an afterlife.

Although neither Cindy nor Irene actively participated in, or identified with specific organized religions, they each coped with the finitude of life by holding onto a belief in an afterlife and hope to meet deceased loved ones again. Irene reasoned "I do believe that when you die. Some way, somehow, consciousness. Souls. Whatever. Do meet again and interact in some ways, has got to be something. I don't believe that when you die, that's it, black forever. I think there must be something" (#9:475-477). Irene shared how her mother was a regular churchgoer who believed in speaking with the dead via spiritualism. Irene commented on how calm her mother appeared as she was dying, linking this to her mother's lack of fear during the process. Irene visited a spiritual medium after her mother died and felt she had connected to her spiritually, leaving her feeling reassured that her mother was indeed in an afterlife. Irene shared how this experience helped her cope with facing her own mortality and negated her fear of dying (#9:479). Although Irene is not

afraid of her own death, she holds anxiety about the impact her death might have on her children, showing how meaning of death is contingent upon context (#9:481-482).

Cindy also spoke of her belief in a higher power and how this helped her cope with thinking about death. In addition, Cindy shared how her ritual of lighting a candle and sending a prayer connected her spiritually with her deceased mother, sharing "I felt like my Mum was around me" (#3:288). This continuing spiritual bond, having mother with her on a spiritual level, comforted Cindy and empowered her to cope and feel less afraid of the uncertainty related to end of life.

Yet Cindy also experienced meaninglessness when participating in social activities that ought to have been pleasurable, as she faced into uncertainly of her mortality. Cindy explained, "if I did go, um... and I think... I might die soon and not have this anymore, so I didn't want to enjoy it. I know it sounds a bit bizarre, but it was like, I didn't want to enjoy it, because it might be taken away, kind of thing. Because you know cancer is a wild card, you don't know where it is going to end or... so... I isolated myself at the very beginning (#3:171-173). Cindy coped by isolating herself from friends and family gatherings. She denied herself joy because when she was happy, she also remembered the paradox that all would be lost to her in death. Choosing to isolate herself allowed Cindy to cope using avoidance. She also coped by dwelling in the negative emotions of anticipatory grief, thinking about what she would miss when she was gone.

Jean identified with "the spiritual side of things rather than a religious thing" (#10: 477); she considered herself to have a solid spiritual connection based on her energy healing practices, including Reiki, that she had regularly performed on others before her breast cancer diagnosis. Since then, Jean has felt abandoned by her spiritual connection and experienced a crisis of faith, resulting in meaninglessness. To control her death anxiety Jean coped by getting her affairs in order. Recalling a conversation with her daughter Jean explained, "I want to get the power of attorney sorted out...I need to give you all my bank details and things. Just in case. And she said nothing's going to happen and I said, but I need to know that I am prepared" (#10:508-509). Jean reasoned "before I felt invincible. And I don't feel invincible, and you just think, you know yer, yer time is limited you know"

(#10:510-511). This example shows how Jean experienced existential anxiety related to death and how she coped by controlling what she could. Although Jean identified as a seasoned mindfulness meditation practitioner and teacher, paradoxically she found it challenging to practice in the face of existential anxiety. Jean also spoke about feeling disconnected from other energy healing practices such as Reiki and working with crystals that had somehow lost all meaning for her. This crisis in meaningless left Jean reeling, temporarily not knowing how to cope. Fortunately, Jean sought professional help by engaging in psychotherapy to help her to adjust to changes in her beliefs and values.

Fay did not report any spiritual beliefs or practices, but she did attend mindfulness meditation courses, although remains ambivalent about the usefulness of them. Ironically Fay shared that her coping mechanism to get through the most difficult times was "go and make a cup of tea and think about what you are doing. Stay in the moment, and stop going off... into the distant future, where you are, you know. Dead. Um. So. Yeah" (#6: 528-529). The practice Fay described is an excellent example of mindfulness meditation in action, by simply staying on the task at hand, making her tea, she could cope and hold her death anxiety at bay.

# 4.4.2 Spiritual Support in Complementary Therapies

Cancer support charities in the UK offer access to a range of complementary healing therapies, including but not limited to meditation practices, reflexology, Reiki, therapeutic massage, and acupuncture. Study participants shared how they benefitted from these alternative therapies. For example, Heather and Beth turned to complementary healing practices for support. Neither participated in organized religion, but instead found it meaningful to address their mind-body balance with therapies like reflexology and massage.

Irene did a six-week mindfulness course and reported how it helped her cope with her emotional wellbeing (#9:353-357). Irene explained how mindfulness helped her to cope by choosing what to focus on. She recognized that trying to hate her husband was not helping her, so she

decided to let go, or push negative emotions such as anger and hate aside, and instead opted to look at good things in her life such as her relationships with her children, friends, and family. Mindfulness practices can facilitate coping processes such as adaptation to problems using acceptance and cognitive restructuring.

Gail also found meditation helpful to cope with anxiety, particularly deep breathing exercises and physical activities like yoga, running and swimming. She also took advantage of aromatherapy and reflexology on offer at her cancer support centre. Gail believes that these activities helped her to take time just for herself, to focus on her wellbeing. She sees this as positive action, recognizing her default coping strategy as "busy worrying about everybody else" (#7:298-300). Gail coped by finding new meaning in allowing room to be kind to herself.

Allison shared her experience of how Reiki helped her heal from the trauma of surgery and begin the journey to accept her reconstructed breast. A ritual to welcome the new breast was performed during a Reiki session for Allison, who had been unable to cope with looking at her changed body without feeling disgust up until this event (#1:446). The healing powers of touch therapies also helped Beth reconnect with her body after surgery and treatment. Beth acknowledged her bias as she works in this field, however, strongly believes in the importance of human touch and in focusing on self-care as a way of coping during recovery after illness.

# 4.4.3 Meaning Focused Coping

The findings revealed how all participants engaged in meaning focused coping strategies.

These included realigning priorities, benefit finding, finding meaning in ordinary events, and meaning attached to legacy.

i) Coping by Realigning Priorities. Cindy shared how she coped by adjusting her behavior after self-reflection and realigning her priorities, "I used to do a lot for other people. I am trying to put myself first in that respect now" (#3:187). Cindy explained her role in her family as the person to

turn to in a crisis, she helped others sort out their problems. Since having breast cancer Cindy realized her limits and her need to save her energy for her selfcare (#3:191-193).

Beth echoed this sentiment in her new attitude "evaluate what works, what doesn't work, don't take prisoners, so that is the positive it's a real positive thing about cancer (#2: 169). Beth was able to apply her coping philosophy to adjusting her work schedule; she decided to leave one job and reduced her working hours by half in the other, leaving her with the option to add more hours as and when she feels able (#2:165).

Irene was still co-habiting with her ex-husband when she got her breast cancer diagnosis, the relationship had deteriorated to the point that they led separate lives, albeit under the same roof. Irene made a conscious decision to prioritize her health before focusing on formalizing the end of her marriage, "I just thought, oh you know what, this, there's... more things to worry about than trying to sort him out" (#9:224-225). Irene's priority was her physical health, she needed to regain her physical strength first before she could turn her attention to coping with issues in her interpersonal world.

Emma realigned her priorities by focusing on self-care by not rushing back to work before feeling physically and psychologically fit enough. Emma found this problematic because she found herself sitting with conflicting values. As a police officer Emma reflected on her work ethic that combined her sense of duty with a moral value of needing to help others (#5:575-576). Emma faced feelings of guilt and shame for being away from work on sick leave, and she was certain that her GP would deny her request for an extra two weeks off. Emma was astounded when the GP telephoned her, insisting that two weeks was not long enough, suggesting she had at least another month out of work to recuperate. This finding is important because it highlights how values that can be useful in one context can hold entirely different meaning in another. In this example Emma shows how she coped by prioritizing her health and personal wellbeing over her work identity values.

Fay apologetically used the cliché "I don't sweat the small stuff" (#6:292) as she reflected on how her life priorities had changed since having breast cancer. Fay shared how she was more aware of the things that really do matter, such as her health the people she cares about rather than being caught up in anxieties such as those related to work; "It's just like nobody died. You know. What, what's the worst that can happen in a work situation?" (#6:471). This example shows how Fay coped by adjusting her values about the meaning of what matters the most to her.

Heather also realigned her priorities concerning her former identity as a workaholic. Her breast cancer diagnosis made her realize "not everything revolves around work" (#8:658), leaving her to question the values she held about the meaning of work and her other responsibilities including being a mother, a wife, and a graduate student. Like other participants in this study, Heather now copes by scheduling time to relax and take care of herself. Her new perspective on life is "if you take care of yourself, then, everything... taking care of other people will sort of follow a bit more" (#8:766).

ii) Coping by Benefit Finding. Gail believes that she is stronger and more assertive since her illness. She reflected on her past ability to advocate for others easily but was less able to so the same for herself; "And now, I'm like it for myself. I will, say.... Um. If something is wrong, or... or I'm not quite happy, um. Yeah. Without... dissolving into tears, and not having the strength to do it" (#7:358-359). Gail highlights her change in coping style away from emotion-focused strategies such as crying to a more assertive problem-solving style.

Fay reflected on the paradox of facing mortality during her illness; the difficulties and fear she experienced have resulted in a changed attitude. Fay no longer coasts through her life; she reports how she now lives more purposefully, being more engaged with the quality of her life. However, the most important revelation for Fay was recognizing her resilience and how well she coped, using the metaphor of how she is still standing stating; "what I have been left with is, is an understanding that I can cope just about anything" (#6:473).

Beth found her voice and courage to do a podcast about breast cancer and the benefits of complementary therapies. She explained how her cancer diagnosis was a catalyst for her changed attitude. Before having cancer, Beth thought, "oh I couldn't do that" but now asks, "hey why not? What's the worst that can happen?" (#2:240). Beth finds new meaning in being brave enough to try new things, showing her courage to take a risk without being attached to the outcome as a benefit of her cancer experience; believing it is better to try and fail than never to try at all.

Allison experienced a sense of newfound strength and courage related to reaching out to others for support. Before having cancer, Allison was influenced by her understanding of negative cultural biases linking the need for psychological support to weakness or caving in under pressure (#1:226). Through individual psychotherapy Allison has discovered her capacity for self-care and new appreciation for her life. Similarly, Emma has experienced positive benefits from attending group therapy. Emma became more able to tolerate paradox and ambiguity in her group work, stating "it helps thinking, well I can be angry about that, but I can also have gratitude too" (#5:671). Emma sees benefits in being able to be more open to sitting with 'both- and' type scenarios.

iii) Coping by Feeding the Soul and Finding New Meaning in Ordinary Events. Heather spoke of feeding her soul by engaging in activities that brought her joy such as joining a singing group and her passion for running. Fay also finds meaning and enjoyment in simple life pleasures, "I would be quite happy, with a, you know a walk, in nature, or sitting by the sea, or doing something with animals" (#6:463-465). Fay shared how she coped during her chemotherapy treatment by trying to include joyful activities in her daily life to make the most out of the days she did feel well (#6:46-47).

Beth recalled a conversation she had with her son while walking by a river, appreciating the wonder and beauty of the day. Beth recalled how she noticed how other people nearby were experiencing the same scene differently; "they're all like this, looking at their phones, I said to him they are missing it all, they're walking through life missing the beauty of it" (#2:251-253). Beth found new meaning in her appreciation of nature, going for a walk along the river made her feel more

connected to life itself. Beth shared how her cancer experience made her more aware of what really matters to her as she realized the power of living in the present moment and savoring life in her own back garden, "it's actually here, breathing in and out, feeling the sun" (#2:262). This new appreciation of everyday moments in the natural world helped Beth to adjust her values; no longer taking her life for granted, she could see the specialness in life.

The sea is significant for Gail, who eased her death anxiety by relocating to a new home with a sea view, "I want to die looking over the sea! (laughs) but no, I mean, you know. Seriously, it was like that, you know" (#7:440). Gail's example shows how she coped with facing mortality by making conscious decisions about her physical living space, controlling everything she could, allowing her to make the most out of the time she has left. Coping by finding meaning in nature speaks to the importance of the natural physical world as a healing resource, a sentiment echoed by Irene as she appreciated the rhythm of life in the changing seasons noticing as she walked her dog: "you know it's spring again, there's the spring flowers, the trees are turning green" (#9:372-373), pointing to the interconnectedness of humans as part of the natural world.

iv) Coping by Finding Meaning in Legacy. More than half of the participants discovered a new sense of purpose in life and a desire to leave a legacy. Beth, Cindy, and Fay, each felt compelled to support others facing breast cancer in future. Beth felt humbled by both her work with other cancer patients and her own cancer treatment experience. Her gratitude for the excellent care she received inspired her to want to do her best for others to pay back for being well cared for by the health system (#2:235). Beth also started a podcast to share her experiences with others (#2:239), evidencing the meaning she finds in social action and helping other people cope with cancer.

Similarly, Cindy shared her hopes to offer peer support to help others in the future when she feels able to do so (#3:276), due the benefit she had from participating in peer support groups.

Fay expressed her belief that peer support is a vital part of breast cancer recovery and that there is a responsibility to give others accurate information and not engage in fear mongering "I have a responsibility to others coming after me to not, put the fear of god into them" (#6:411), but

instead share tips on coping such as acting as your own advocate, reaching out and getting help from trusted sources such as the medical oncology team, counsellors, and peer support groups connected to cancer charities. Fay also recommended being assertive and avoiding people who wanted to share negative cancer narratives (#6:431). Participating in this research project also gave Fay a sense of legacy, as we discussed possible risks from participation Fay said; "I wouldn't have volunteered if I weren't, if I thought it was going to do me any harm. Um. And you know, it comes back to legacy don't we, and if there's anything I can do that will help people coming after me then I'm, I'm all for it" (#6:643-645).

Jean also spoke of the meaning she derived from being a participant in this study "it's a nice way of paying forward and I thought that's exactly what, why I wanted to do it" (#10:633) she shared her hopes that others might benefit from her insider knowledge (#10:637) and valued the idea of "just being able to make a difference" (#10:678).

# 4.4.4 Summary of Findings in the Spiritual Dimension

The spiritual dimension findings support the notion that coping is part of a process of making sense out of life, of finding meaning in terms of the grand scheme of things. The findings illustrate how participants experienced meaning related to spiritual beliefs and values. As each faced breast cancer and existential concerns, fresh perspectives materialized about the people and things that really mattered to them. Meaning-focused coping such as realigning priorities, benefit finding, seeking healing support from others, engaging in soul soothing activities such as meditation practices and finding meaning in nature are some of the ways participants coped and adjusted to change. The final super-ordinate theme explores participants' experience of time and how time is integrated into the fabric of life in across all dimensions of existence.

### 4.5 Super-ordinate Theme 5: Coping and the Experience of Time

Everyone in the study reported an understanding of time as a multidimensional phenomenon. All participants shared experiences related to their perception of time during their illness that included the past, present and future dimensions of time and was not limited to linear measurement. Three sub-themes emerged from the data. The first shines light on the perception of the speed of time. The second surveys the meaning of time while facing mortality. The third theme addressed the interpretation of the timing of events in the context of the personal and the broader social world, for example, the timing of psychosocial support services and the impact of coincidental events that participants linked to their narratives.

## 4.5.1 Perception of the Speed of Time During Treatment

The findings related to coping with the perception of time during breast cancer suggest that the focus on physical treatment and survival came first in the hierarchy of coping and that adjusting to the facticity of breast cancer took a longer time to assimilate into individual worldviews. The findings' important clinical implications question the timing of processing initial shock and trauma related to breast cancer diagnosis in tandem with making important treatment decisions.

i) Initial Shock of Diagnosis Related to Time. Allison described how the initial shock of her diagnosis "took time to sink in" (#1:11), pointing to her efforts to cope with making sense of the meaning of having breast cancer and how her perception changed as she adjusted over time. Beth echoed this finding with her use of the metaphor of being "drip fed" information, explaining how this helped her to cope with the news of her diagnosis, "because you actually can't take it all in" (#2:78-80). In addition, Beth described the speed of change in perception from being well one day to being ill with a life-threatening disease the next in metaphorical terms. The symbolism of eating suggests the enormity of the meaning of her breast cancer diagnosis; it was complex information for

her to digest, hinting that coping was related to time in that it took time for her to come to terms and cope with the changes in her life.

Gail shared how she felt she was "still in shock" (#7:310) for a long time after her diagnosis, pointing to a delayed psychological reaction. Heather shared a similar narrative, "I think the emotional side of it didn't hit me till a long time afterwards really" (#8:119). Irene elaborated further, "when you are told; you don't really have... sounds silly to say you don't really have time to think and consider" (#9:50). Irene's insight points to the hierarchical nature of coping, suggesting that coping methods focus on the most pressing need at the time. For example, Irene had to choose her treatment options quickly, and she did not have time to spend researching the pros and cons. Instead, Irene coped by following medical advice, interpreted as a problem-focused coping style. These findings point to the timing of processing initial shock and trauma related to breast cancer diagnosis, suggesting that the focus on physical treatment and survival comes first in the hierarchy of coping and that adjusting to the facticity of breast cancer took time to assimilate into individual worldviews.

ii) Coping with Waiting for Surgery and Test Results. The length of time between diagnosis and start of treatment for participants varied. Still, each study participant reflected on time feeling slow when waiting for confirmation of results and then moving faster once treatment commenced. One important finding concerns the participants' choices about their treatment options at this crucial time, just after diagnosis. Jean waited over three months for a definitive diagnosis; she felt impatient while waiting and made a conscious effort to try not to worry. Jean coped by avoiding thinking about the possibility of breast cancer, even though she knew that it was a possibility. This knowledge did little to buffer the emotional charge experience upon confirmation of her diagnosis. Jean felt pressured when given only five days to decide on the type of reconstruction surgery she preferred (#10:102-103). Jean shared how she coped by reaching out to a trusted friend who was also a medical doctor for advice; this is an example of seeking professional help with a problem-solving coping style.

Although Allison had her surgery within four weeks of diagnosis, she reflected how this seemed fast and observed that it did not leave her much time to prepare or think about everything. Allison initially coped by ignoring the information packet given to her by the breast cancer nurse and avoided meeting with the support nurse assigned to her. Although avoidance can be linked to denial, Allison coped by refusing to think about her cancer diagnosis and instead carried on with her life as best she could right up until her surgery. Allison shared how she coped with her fear by using positive self-talk while driving to work and shouting at her breast cancer, "you're not having me!" Internal dialogue is a form of tension reduction and an emotion-focused coping style.

Debbie also recalled how in hindsight, she did not have enough time to research her surgical options (#4:107) and made her decision influenced by her need to have her cancer removed from her body as quickly as possible (#4:579). Debbie coped using a problem-solving style that allowed her a sense of control while addressing her need to irradicate the threat of cancer from her body. The timing of selecting treatment options shows an important finding highlighting how participants had to make vital decisions within a limited time frame while also experiencing an initial state of shock. This holds potential implications for future mental health. Jean and Debbie wished they had had more time to research surgical options before making decisions. They regretted that they were not better prepared for the potential long-term physical and psychological repercussions.

iii) Coping with Time Experienced During Chemotherapy. Participants reported how they experienced time differently depending on the context of their treatment. The five participants who underwent chemotherapy shared how they needed to adjust to living within a three-weekly cycle. Treatment entailed going to the hospital for a day to have intravenous drugs, then feeling unwell related to side effects for a week or so, then feeling better for a few days just in time to begin the next round of chemotherapy. This cyclical pattern went on for six to nine months, with each treatment having an accumulative effect, leaving them a little more tired each time. Participants shared how they coped by adjusting their lives to accommodate this cyclical pattern. For example, Fay coped by taking advantage of when she did feel well by going out for meals and seeing family

and friends (#6:318). This way of coping by seeking relaxing diversions was a temporary solution, but it did not negate her low mood during difficult days. For example, Fay spoke of feeling so ill that she despairingly told her sister that she wanted to die during an awful ten-day period. The cycle of chemotherapy left Fay feeling paralyzed in time, "Because I felt that the world was, was going on, without me. People were living their lives, and I was in this, stuck in this three-week cycle" (#6: 325-326). Fay coped with her lived experience of being stuck in time by dwelling in the negative. This left Fay feeling that she could not cope, and at her lowest point she entertained the idea of death as a possible solution to her problem.

Heather had a similar experience of feeling wretched as chemotherapy's accumulated fatigue and side effects pounded her body. She found herself being unable to move off the sofa for days on end, "I literally I made a dent in the sofa over those few months of just literally, we've got a long bit sort of a bit like a chaise longue bit on our sofa, and I literally parked myself there. For a few months" (#8238-239). Heather's use of the term parked implies being stationary, going nowhere. Heather experienced a sense of frozen time like Fay, and she also coped by dwelling in the negative. Coping by sitting with worry about current and future events and ruminating in negative thoughts ironically helped Heather to reflect upon and acknowledge her fear that the side effects of chemotherapy might kill her. Heather concluded that the treatment was doing her more harm than good and decided to stop chemotherapy against medical advice. Heather coped by making this choice in response to reduced quality of life, guided by her innate experience of loss and the perceived threat to her future. These emotion-based coping strategies enabled Heather to think deeply about her lived experience and decide on her cancer treatment.

iv) Coping with Time Experienced During Radiotherapy. The five participants who required radiotherapy reported how time was perceived as slow and dragged out during this phase of treatment. Heather said, "So your whole day was taken up, you know, by the time I'd driven there, hung around for a couple of hours, it took five minutes to actually do it. And then come home again. So your day was completely screwed basically" (#8:302-303). Heather coped by dwelling in the

negative, feeling disgruntled over her perception of wasted time. The other participants also found their time consumed during the prescribed fifteen-day protocol of radiotherapy. Gail was the only participant with a shorter five-day course of more intensive stereotactic radiotherapy treatments. Still, she also reported that time seemed slow (#7:204), pointing out, as the others concurred, how it took more time to prepare and position her in the machine than it did to do the actual therapy. Coping with the sense of wasted time fed into broader concerns about limited time and mortality, addressed in more detail in section *4.5.2. Meaning of Time Shaped by Mortality*.

v) The Experience of Ambiguity of Time. Recovery after surgery left participants with a sense of ambiguity as time took on both slowed and accelerated qualities. Allison recounted how she recalled the speed of her hospitalization for mastectomy and reconstruction surgery as "in one day and out the next" (#1:127). In contrast, she observed that it had taken nearly a year since her surgery to recover. Debbie spent three months after her mastectomy and DIEPP Flap reconstruction surgery coping with a donor site wound that was slow to heal, and Beth spent over six months dealing with recurring surgical site infections. The common theme for nine participants was the sense of slowed and lost time concerning their breast cancer treatment. Only Irene reported the opposite effect, "I don't feel it [time] has slowed down while I was having cancer treatments.

Although it is obviously nice not having to work. Something filled those days (laughs) I don't necessarily know what" (561-563). This comment is interesting in that although Irene's perception of time did not change, she has no definite memory of how she spent her time; it is as if time just melted together. This could be interpreted as a type of trauma response. Alternatively, it could be related to a phenomenon commonly referred to as chemo-brain, where cancer patients report dulled cognitive effect and absentmindedness.

vi) Coping with Anxiety Related to Time. Eight participants shared how they coped with anxieties related to having breast cancer by living in the present, while others paradoxically focused on the future to deal with the present moment. Fay used the cliché, 'one day at a time' as she described how she navigated life during treatment. Fay faced anxiety if she ventured too far ahead,

thinking about potential future catastrophes. Fay realized that using the coping strategy of worrying about both present and future concerns increased her anxiety. Fay coped by focusing on her current state to manage stress, using mindfulness techniques. Cindy, Allison, Beth, Irene, Emma, Jean, and Gail agreed that worry as a coping strategy was unhelpful primarily; however, each used different coping strategies to settle anxiety. For example, mindfulness meditation helped Gail, particularly when her anxiety peaked at night. Complementary therapies such as massage helped Beth cope with feeling dissociated from her body. Psychotherapy helped Jean, Allison, and Emma come to terms with their experiences of anxiety. Others such as Fay and Irene coped by seeking peer support and spending time with friends and family. In contrast, Heather and Debbie coped with difficult days by wishful thinking and holding on to hope, easing anxiety by focusing on a future where they imagined brighter days ahead.

## 4.5.2 Meaning of Time Shaped by Mortality

All participants shared new awareness of the limits of life and how they wanted to use the time they had left. Participants coped by adjusting priorities and finding meaning in the intentional use of time by reviewing their values and considering what mattered to them. Allison realigned her priorities to make time for herself (#1:399). Beth found new meaning in taking time to pause and notice nature feeling the sunshine and the breeze (#2:250). Cindy realized how she wanted to spend her time with loved ones rather than rushing out to work (#3:297). Debbie had an epiphany and chose to give up work to spend her time doing more personally meaningful activities (#4:438). Emma shared feeling pressure to make the most of her time and not waste it (#5:227). Fay questioned the meaning of her life and what her legacy might be (#6:489). Gail moved house to spend more time with friends and look out upon the sea every day (#7: 443). Heather holds a new 'seize the day' attitude; she is not prepared to wait until retirement to enjoy life, choosing to try new activities in the here and now, such as joining a choir (#8:670-671). Irene is enjoying her life, sharing her

philosophy not to sweat the small stuff (#9:389, 392), and Jean looks forward to getting back into her energy healing practices that gave her life meaning before she got breast cancer (#10:460).

All participants in the study experienced a personal awareness that death was no longer only for others. Allison stated, "I can see the finishing post, you know, I've never allowed myself to even look at the finishing post. But I can see it" (#1:352). Allison reflected how the past thirty years went by quickly and how her cancer experience has been a wake-up call that has helped her to appreciate all she has in her life. Allison shared the added meaning of approaching age sixty and how she is motivated to "do this right" (#1:319), meaning to do her best to take care of herself in the hope to get another thirty years of life. Although Allison is more death aware, she also reveals a degree of death denial using the term 'finishing post' as a metaphor for death and how she does not "really want to gallop towards it that quickly" (#1:353).

Debbie coped with her ambiguity and uncanniness related to mortality sharing, "I feel like I am running out of time, but I don't know, I might not be. But I just... because I don't know, I just have to keep packing loads of things in" (#4:509-510). Her words suggest coping by living life to the full. Debbie also shared her epiphany that the things she now chooses to do are more meaningful such as retiring from a managerial role to spend time fostering young single mothers with babies (#4:438).

Two participants shared how they coped with the threat to their mortality during treatment by focusing on the future to cope in the present. Debbie held on to her hopes to see her unborn grandchildren and dreamt about all the places she wanted to visit in future travels (#4:461). Heather wrote lists detailing how she envisioned her future beyond her breast cancer treatment, planning and focusing on positive things she wanted to do, like visit her brother overseas and thank all the people who had helped her. She shared how she promised herself, "once I get through this rubbish time, at the end of it, I am going to do something really fab" (#8:369). This way of coping by imaginal living in the future time is different from narratives of coping by living in the present while holding onto hope for better days ahead.

Coping with mortality left most participants hopeful that they could adjust and make use of their time to lead more meaningful lives going forward. However, Emma and Jean held more pessimistic views for the future. Emma convinced herself that statistically, she would be one of the fifteen out of a hundred women with breast cancer who do not survive long term, estimating that she might only live for another fifteen years. This constraint on her future time has left Emma feeling pressured not to waste her time, resulting in increased anxiety and ruminating self-reproach as she is caught in a self-fulfilling prophecy. Emma wants to make the most of the time that she thinks she has left, but her lived experience is paradoxical. Emma describes her situation, "the pressure to do that when I'm tired... I mean this circle; it's kind of a self-fulfilling thing. So, I must enjoy my life because I've had this awakening and blah blah, but then I feel so tired, that I can't [enjoy my life] and then at the end of the day... well, that's another day that you've wasted of your life (#5:227-228). Emma struggled with an existential crisis of meaninglessness and the clinical implications for such a state of being, hold a high risk of depressive illness. Fortunately, Emma coped by reaching out for professional support and attends peer-support groups.

Jean also struggled with low mood during her breast cancer treatment requiring professional psychological support services. Jean looks to her future, aware of the limits of her physical body related to post-surgical disability and ongoing hormone replacement therapy, which she views as constant reminders of having had cancer. Unlike other participants who look to the future embracing new hopes and dreams, Jean is more concerned with recreating her past life. She wants to "get back to things" (#10:463) yet holds the knowledge that she might never be the same again. Holding on to the past is more meaningful for Jean, who hopes to return to her former self, regaining the strength in her arm and ability to do yoga and her energy healing work that held meaning (#10:460-462). Those were her passions, the goals that she had for 'her time', that time during adulthood when women can reclaim life as an individual. Jean did a fine job raising her children. Just when they were all grown up and she was about to have more time for herself, was when breast cancer thwarted her, leaving her feeling disconnected and abandoned by the things

that held meaning for her. These findings illustrate how a crisis of meaninglessness can emerge in the face of mortality and are clinically significant for psychologists working with women recovering from breast cancer.

### 4.5.3 Context of Time

The third subtheme addressed the interpretation of meaning related to the timing of events in the lived experience of the participants, such as timing and access to support services and the experience of time at critical points related to follow-up health checks.

Two crucial findings emerged regarding psycho-oncology support provision. The first was that although all participants reported that they had at least one meeting with a breast cancer nurse specialist during the early stages of treatment, most participants said that they needed more psychological support during the later stages, mainly when discharged from oncology services. Jean shared her experience of being released from services, "on you go, we don't need to see you anymore, just phone me if you need me, and it was then I really kinda crashed" (10:325). Jean had formed an attachment to her breast care nurse, and the end of this relationship was difficult for her. Endings or ruptures in relationships of any kind can be a source of stress, as people cope with feelings of loss that can heighten fears of abandonment and isolation. Jean has a personal history of disrupted attachment, so a clinician interpreting her reaction using attachment theory would be prepared for Jean's psychological response and would have explored the meaning of endings with her at the beginning of the therapeutic relationship. Existential practitioners also encourage exploration of the meaning related to endings since limit situations are considered givens of existence.

Cindy shared a different view about the timing of attending support groups. She shared how she participated in a group before starting treatment and had a terrible experience. She was traumatized taking in the scene, seeing the other women with no hair in various stages of treatment. Cindy panicked as she realized the implications of the chemotherapy treatment she was about to

begin, and for the first time, saw herself as a woman with breast cancer. Later after she completed her treatment, Cindy returned to the support group. Time had passed, and with time she had adjusted to her situation and reported significant benefits from the peer support on offer.

The second finding was related to the types of support available to help women cope as they adjust to living with breast cancer. Psychological support in a peer group format was the most reported. These groups were free of charge to all participants as they are facilitated by breast cancer charities and other community-based breast cancer groups. Some participants such as Fay, Jean and Irene were able to access short term individual psychological therapies provided by cancer support charities. Still, these were time-limited, averaging only six sessions. Allison was reluctant to attend groups, and there was no provision for individual support in her local area. Allison chose to self-fund ongoing psychotherapy and complementary therapy such as reiki for her wellbeing during her breast cancer recovery.

Complementary therapies for wellbeing are available through the health service and cancer charities, depending on geographical area. The demand for specialist massage services such as lymphatic drainage affected the three participants who had post-treatment lymphoedema complications. Fay shared how she could only access limited appointments for this specialist massage through the health service, leaving her to pay a private practitioner for these necessary services. These findings point to potential economic disparities for women with long term physical and psychological repercussions from breast cancer treatment. They also point to the importance of timing; group support is not always the right fit for everybody all the time, as evidenced by Cindy's experiences of attending a peer support at different times during her cancer journey.

ii) Coping with Follow-up Health Checks. All participants reported how their situational context was linked to changes in perception of time, particularly the need for ongoing medical checkups and the need to take hormone therapies for extended periods between five and ten years. For example, Fay shared how time took on new meaning and slowed when waiting for results after scans and blood tests during ongoing health checkups. She shared her anxiety at those points and

how her cancer "becomes very real to me again, but I think I am doing a really good job in-between times of living my life" (#6:604-605). Fay considers anxiety to be a waste of time, so she copes by facing into her anxiety only when she needs to at specific points in time, then lets it go and gets on with living her life until the next time she is interrupted.

## 4.5.4 Summary of Findings Related to the Experience of Time

All participants reported changed perception of the speed of time that ranged on a continuum depending on the context. Time held meaning for participants as they faced mortality and realized that life was limited. This awakening to this existential given pushed them to think about how they wanted to spend their time going forward, and what really mattered to them. Ways of coping in relation to time involved facing into mortality and managing death anxiety by accepting the limits of life, adjusting priorities, choosing how to spend time, focusing on the future by holding on to hope and getting on with living. The interpretation of the timing of events in the context of the personal and the broader social world showed that the timing of psychosocial support mattered, with most participants saying that they needed this later in the process as they readjusted to life after treatment was completed. The final finding related to time concerned how heightened anxiety is felt at key points in time such as follow-up appointments and how breast cancer seems more real during these moments and then it fades again into the background again until the next time it is remembered.

### **Chapter 5 Discussion**

This chapter will critically evaluate the study's key findings reflected in the wider literature first in relation to coping theory and then in the context of the coping with breast cancer literature.

The research to practice implications with recommendations on how existentially informed psychotherapy approaches could benefit this population is presented. Reflexivity on the dilemmas of the knowledge journey in the research process will be shared, supporting the validity of the project

contemplating the strengths and limits of the study and methodology. To conclude a synopsis of the key findings highlighting the study's relevance will be argued alongside recommendations for future research.

### 5.1 Discussion of Key Findings

The key findings of this project add to the knowledge about the lived experiences of coping with primary breast cancer. All participants reported breast cancer diagnosis as a physical and psychological crisis and a life-altering event marked by existential distress. The findings revealed the existential nature of challenges faced by the participants and provide insight into how each participant coped with existential givens and concerns. The results are first discussed alongside theoretical coping literature and then they are critically evaluated and reflected into the wider literature concerning coping with breast cancer.

## 5.1.1 Understanding Participants' Coping Methods within Theoretical Constructs of Coping.

In response to the impact of primary breast cancer participants reported multiple coping methods, as presented in Table 3 p.54. The findings are discussed in relation to a selection of theoretical models of coping. The researcher acknowledges that this list of ways of coping in the findings of this study apply only to this sample, and that they could be understood and interpreted differently depending on theoretical framework of coping utilized.

I decided not to attempt to fit the data from this study into preconceived categories of ways of coping outlined in existing theoretical coping models during the analysis of the findings. I was concerned that I might risk losing phenomenological knowledge by reducing them to fit into only one theoretical model. Reducing coping methods into broader categories for other research methodologies or the construction of coping assessment instruments would be appropriate and valuable, but this was not the case for this IPA study. Instead, this study valued individual experience accounts to discover the nuances of coping, acknowledging the risk that phenomenological

knowledge might be lost in reductionist approaches. However, it is essential to acknowledge how the study's findings are situated within the existing knowledge on coping and might add to the knowledge base.

i) Problem vs Emotion-focused coping. The ways of coping reported in this study could be summarized into wider coping styles such as those of the Transactional Model (Lazarus & Folkman 1991,1993). Problem-focused coping is viewed as attempts to change negative emotional states by generating and evaluating alternative solutions. Strategies might include planning, action, or seeking help (Felsten, 1998). Emotion-focused coping aims to reduce or remove negative emotions related to the problem and might include avoidance, distancing e.g., relaxation or wishful thinking, rumination, and seeking emotional support (Felsten, 1998; Tamres et al., 2002). Some of the ways of coping reported in this study could be considered strategies of emotion focused styles such as, focusing on the positive, holding on to hope for the future, worry, rumination and avoiding others by isolating self. While other ways of coping such as seeking help from others like medical professionals or engaging in action to solve problems might align with strategies in the problem-solving style. But there are other examples of coping that are not as easy to reduce to either category. For instance, it could be argued that spending time with friends and family, disengaging from body, and avoiding sexual intimacy could be interpreted as either emotion-focused or problem-solving coping strategies. Avoidance is considered an emotion-based strategy so avoiding sexual intimacy enabled Allison to also avoid facing feelings of self-disgust, yet this could also be seen as a problem-based strategy since the action of avoidance was generated to cope with negative feelings of body shame.

ii) Approach vs Avoidant Coping. Carver et al., (1989) describe avoidant versus approach coping styles. Avoidant styles include strategies of denial, substance abuse, venting, behavioural disengagement, self-distraction, and self-blame. While approach coping styles are framed as active coping, positive reframing, planning, acceptance, seeking emotional support and seeking informational support. The ways of coping with dilemmas in the physical dimension in this study could be interpreted using avoidant vs. approach coping theory. For example, Cindy shared how she

continued to smoke cigarettes even though she knew it was not good for her health. This could be understood as a type of denial, or substance abuse and labeled as an avoidant style; yet Cindy explained that her cigarette smoking held meaning for her; the activity connected her to her sense of self and allowed her to feel normal if only for a few minutes.

iii) The Responses to Stress Model. Compas et al., (2001b) offer three dimensions of coping; engagement vs. disengagement, voluntary vs. involuntary, and primary control vs. secondary control as an extension of voluntary coping. Engagement coping responds towards a stressor such as in problem solving while disengagement involves responding away from the stressor for example distraction. Voluntary coping needs a conscious effort such as problem solving or cognitive restructuring while involuntary coping is described as a temperamentally based concept with conditioned reactions such as emotional numbing, rumination, and intrusive thoughts. Voluntary coping can be further understood as either primary or secondary control coping. Examples of primary control coping are aimed at altering objective conditions like problem solving or emotional expression. Secondary control coping is about adapting to problems using concepts like acceptance or cognitive restructuring. The Responses to Stress Model offers useful constructs that could classify the ways of coping participants mentioned in the personal dimension of this study, like cathartic release of emotion, distraction to avoid cancer worries, and acceptance of a changed body. Cathartic emotional release could be an example of primary control. Distraction to avoid cancer worries would be an example of disengagement coping. While acceptance of a changed body might be seen as cognitive restructuring and secondary control coping to change the meaning of the event.

iv) Self-Regulatory Model of Illness Behavior (SRM). This framework aims to understand how symptoms and emotional responses to illness threats guide coping behavior. It is based on commonsense approaches to problem solving and suggests that illness is dealt with in the same way as any other problem (Leventhal & Nerenz, 1980; Leventhal et al., 1997). The three-step process involves interpretation to make sense of the problem, the use of approach or avoidance coping to deal with the problem to regain a state of equilibrium and thirdly appraisal to assess if the coping

strategy was successful or not. SRM could have been used to frame this study; for example, participants initially interpreted a change in breast tissue as a potential threat and went to seek medical advice resulting in a diagnosis of breast cancer. To cope and adjust to their diagnosis using approach coping involves examples such as taking medication, talking to friends, and resting, while avoidance coping could include denial or wishful thinking. Appraisal to determine the effectiveness would then determine what coping strategy to try next. I would argue that this model, although valuable for some types of health problems, cannot adequately address the complexity of coping illustrated in this study, particularly problems such as existential distress and mortality salience in fear of recurrence of disease.

v) Crisis Theory. An integrative conceptual framework is offered by Crisis Theory (Moos, R. & Billings, 1982; Moos, Rudolf H., 1984; Moos & Schaefer, 1989) to understand coping with physical illness. Serious illness is conceptualized as a life crisis that requires cognitive appraisal to engage in adaptive tasks by applying various coping skills. The theorists recognize the influence of demographic and personal characteristics of individuals, type of illness and the physical and social environment in which they are situated. Seven adaptive tasks are listed, divided into illness related and general tasks. Illness related examples are dealing with symptoms, dealing with hospital procedures, and developing relationships with medical professionals. General tasks are related to maintaining emotional balance, preserving self-image, continuing relationships with family and friends and preparing for an uncertain future. Three major types of coping skills are offered. Appraisal -focused coping includes cognitive redefinition, cognitive avoidance, or denial. Problemfocused coping examples are seeking information and support, taking problem-solving action, and identifying alternate rewards. Emotion-focused coping focuses on affect regulation, emotional discharge, and resigned acceptance. Crisis theory resonates with my study's findings by supporting the view that breast cancer is a serious life crisis. Participant's ways of coping, particularly those related to the physical and personal dimensions of life could readily align with the major types of

coping skills outlined above. However, I would argue that crisis theory does not accommodate meaning-focused approaches to coping appearing restricted to a constructivist cognitive paradigm.

vi) Adjustment to Physical Illness and the Theory of Cognitive Adaptation. An alternative framework for understanding coping suggests that the three processes to cope with the threat of illness are a search for meaning, a search for mastery and a process of self-enhancement (Taylor, S. E., 1983; Taylor, S. E. et al., 1984a). Taylor et al hypothesize that meaning, mastery and selfenhancement are needed to develop and maintain illusions that enable a process of cognitive adaptation. The theory describes individuals as self-regulatory and motivated to maintain a state of balance. This theory is important and relevant to this study because it was grounded in experiences of women coping with breast cancer, albeit published over forty years ago. The search for meaning involves seeking answers to questions about causality and implications of illness. These questions resonated with the findings of the participants in this study, particularly in the beginning when first diagnosed, study participants worried about both present and future concerns. The search for mastery is described in terms of control, particularly focused on finding ways to prevent symptoms from recurring. This type of coping was evident in my research for example when Emma wrestled over taking her hormone therapy medication even though she did not like the side effects. Taking her medication was a way for her to gain a sense of control to help stop recurrence of her disease. The process of self-enhancement helps explain social comparisons that people make when thinking of themselves compared to others in similar situations. This was apparent in my study within the social dimension of experience. Comparing herself positively to others enhanced Allison's sense of wellbeing as she told herself how her situation could be much worse. Paradoxically sitting in the role of negative comparison left Fay feeling hopeless and helpless as she felt used when others compared themselves to her. Emma compared herself negatively with others as she judged her chances of survival. The final concept posits illusions as understandings of illness that are deemed necessary for cognitive adaptation. Illusions are the individuals' positive interpretations of their views of reality as a way of coping with difficulties. I used the term cognitive restructuring to

describe how all study participants reported coping within the personal dimension, helping participants adjust to experiences of an altered sense of self. The term cognitive restructuring is considered similar to cognitive adaptation described in the theory of cognitive adaptation.

vii) Meaning-focused Coping. Building on existing coping theories researchers noted that meaning and purpose can be attributed to a stressful event alongside positive emotion (Folkman & Moskowitz, 2000; Folkman & Moskowitz, 2007). Examples of meaning-focused coping include realigning priorities, adaptive goal processes, benefit finding, benefit reminding and infusing ordinary events with meaning. Meaning-focused coping also includes adaptive goal processes and cognitive restructuring (Folkman & Moskowitz, 2000; Folkman & Moskowitz, 2007; Park & Folkman, 1997). Of all the coping theories, meaning-focused coping resonated most with the findings of this study. There were many examples of meaning-focused ways of coping particularly in the ways participants described coping linked to the social and spiritual dimensions of life. This is not surprising because it is in relationships with other people in the social dimension and how we view our place the wider world that we make sense of life. The findings of this study extend meaning making coping from an existential perspective to include the category of finding meaning in care. Meaning in care could be reduced to the category of finding meaning in ordinary events but I would argue that the human capacity for caring for others and the need to be cared for are important concepts and deserve a separate category because they are different from finding joy in eating a favorite food or walking a dog.

viii) Existential Coping. To operationalize the search for meaning in spirituality that is not connected to religiosity, Ahmadi offers the term existential coping to describe coping strategies that include: Spiritual Connection with Oneself, Spiritual Sanctification of Nature, Positive Solitude, Empathy/Altruism, Search for Meaning, Visualization, Healing Therapy, Spiritual Music, and Meditation (Ahmadi, 2006; Ahmadi et al., 2017). These coping methods are supported by Frankl's (1959) perspective on meaning that has cognitive origins; to avoid falling into meaninglessness humans cope by assigning meaning to their lived experiences to restructure their worldviews. The

findings of this study, align closely with Frankl's perspective on meaning. They also lend support to three concepts of existential coping. Spiritual sanctification of nature could align with finding meaning nature reported by some study participants. This could also be interpreted as finding meaning in ordinary events as outlined by Folkman & Moskowitz in their Meaning-focused theory (2000; 2007). Parallels could be drawn between finding meaning in legacy, experienced as giving back to the cancer community described by participants such as offering peer support to others with cancer and the existential coping strategy of empathy or altruism. Meditation helped some participants in this study cope with existential distress such as anxiety. Searching for meaning was a major component of the findings particularly in the spiritual dimension of lived experience but also reported across the social and personal dimensions in this study. I would argue that the findings of this study extend the understanding of existential coping beyond coping with spiritual concerns listed above to include finding meaning in care as a new strategy to add to existential coping.

## 5.1.2 Understanding Participants' Lived Experiences of Coping within the Breast Cancer Literature

There is substantive literature about coping with a diagnosis of primary breast cancer, exploring a broad range of topics and sample sets using a variety of quantitative and qualitative methodologies. A Google Scholar search for the phrase 'coping with primary breast cancer' between 2010 and 2022, returned over forty thousand items. In addition, a quarter of these studies have been published since 2018, evidencing that the topic of coping with breast cancer continues to stimulate important research questions from a diverse group of researchers around the globe. It is important to acknowledge this vast knowledge base to be able to meaningfully situate the key findings of this unique study, showing how they contribute to advancing the knowledge of the lived experience of coping for women diagnosed with primary breast cancer.

The magnitude of the literature on breast cancer and coping has been recognized by contemporary researchers who have endeavored to make better sense of existing knowledge using methods such as metanalyses, meta-synthesis, literature reviews, scoping reviews, and qualitative

systematic reviews with thematic synthesis. These scholarly overviews and meta synthesis of evidence provide helpful starting points for novice researchers to tackle reviews of the literature because they point to other pertinent resources. Examples of papers with further literature relevant to this study include important topics such as: coping strategies used by breast cancer survivors (Kvillemo & Bränström, 2014; Lashbrook et al., 2018); appraisal and coping in the efficacy of mindfulness-based stress reduction on cancer patients (Zainal et al., 2013); the impact of medication side effects on adherence to hormone therapy in breast cancer survivors (Peddie et al., 2021); women's stories of living with breast cancer (Smit et al., 2019); the interface between optimism and coping on health of women with breast cancer (Fasano et al., 2020) and the role of spiritual coping in finding meaning in life after breast cancer (Leão, Diva Cristina M R et al., 2022).

An essential focus of the broader literature addresses coping with distress in breast cancer (Arman & Rehnsfeldt, 2003; Drageset et al., 2010; Drageset et al., 2011; Hass et al., 2022; Montgomery & McCrone, 2010; Pilevarzadeh et al., 2019). The term cancer distress is defined by the National Comprehensive Cancer Network (NCCN) (Riba et al., 2019) as "a multifactorial unpleasant experience of a psychologic (i.e., cognitive, behavioral, emotional), social, spiritual, and/or physical nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis" (Riba et al., 2019). This definition of distress is helpful because it corroborates that people with cancer might experience coping difficulties due to potential distress across all aspects of lived experience and acknowledges the need for a whole person approach to oncology care. It is also congruent with the novel methodology of this research project.

To my knowledge this study is the only one to explore the lived experience of coping for middle-aged British women living with primary breast cancer using IPA with an existential heuristic framework. The key findings point to the experiences of coping with existential givens and distress

related to adjusting to living with primary breast cancer from five viewpoints: the physical, personal, social, spiritual, and in relation to time. This analysis attempts to bridge some gaps in qualitative research identified by Laidsaar-Powell et al. (2019). In their meta-review of qualitative research on adult cancer survivors they acknowledge the apparent saturation of research with breast cancer populations compared with other groups of cancer survivors, however, also point to less frequently reviewed topics such as body image, coping strategies and spirituality, and gaps in survivorship topics focusing on side effects, psychological issues, financial toxicity, and health behaviors. The novel findings of this study extend knowledge about coping with primary breast cancer, providing rich detailed accounts of coping physically with side effects of treatment particularly altered embodiment, and raise questions about social justice and health inequalities related to coping with financial stressors. They shine light on the psychological impact of coping with existential givens and an altered sense of self. In addition, the findings point to the importance of meaning as a coping strategy, particularly meaning in care potentially extending current theoretical definitions of meaning-focused coping.

#### 5.1.3 Coping in the Physical Dimension.

The findings related to the physical world provided rich descriptions of what and how participants coped with their embodied experiences and how they navigated the unknown world of hospitals and cancer treatments. Three sub-themes are discussed: a crisis of embodiment, the intersection of coping and economic privilege and implications for social justice and health inequalities.

i) A Crisis of Embodiment in the Physical Dimension. Participants described a complex process of navigating embodied perceptions while simultaneously interacting with other people and things. They report having to cope with managing the cognitive and emotional responses connected to the demands of their physicality and environments. Quality of life can be related to how we are

embodied and manage the tensions between polarities in life, for example, wanting to be healthy but having to cope with illness (van Deurzen & Arnold-Baker, 2005). In response to psychological perceptions of embodiment, participants activated diverse coping strategies to manage physical distress.

Merleau-Ponty declared that it is only through our bodies that we can experience the world, "we are in the world through our body, and in so far as we perceive the world with our body" (1962, p206). There is a duality in perception, as people experience the physicality of their bodies, they also notice the strengths and limits of their embodiment, and it is this that informs part of the sense of self. Breast cancer interrupted the physical sense of self for the participants of this study. All the participants shared a litany of physical side effects resulting from their cancer treatments and described the challenges their bodies coped with both in the short and longer terms. The participants reported being acutely aware of the changes in their bodies, some visible to the outside world, such as loss of hair or change in body weight. At the same time, other experiences were invisible such as loss of libido. The resulting understanding of not feeling at home in their bodies and distress related to reduced self-esteem and body confidence made demands on their coping resources. These findings are consistent with other phenomenological research that acknowledges how the experience of cancer treatment such as mastectomy can affect embodied identity (Brunet et al., 2013; Tighe et al., 2011). This type of phenomenon has been reported in the narrative literature as both biographical disruption and liminality, terms used to describe a state of ambiguity and uncertainty that can be experienced during a cancer journey (Koutri & Avdi, 2016; Liamputtong & Suwankhong, 2015; Thomas-MacLean, 2004; Trusson et al., 2016).

The literature concerning coping with the physical side effects of breast cancer treatment reports similar findings to this study, confirming the need for participants to cope with physical challenges and treatment side effects such as experiences of changed bodies and the long-term implications for psychosocial and emotional well-being (Brunet et al., 2013; Williams & Jeanetta,

2016). They managed physical and cognitive limitations, sleep problems, fatigue, pain, and sexual dysfunction (Harrington et al., 2010; Panjari et al., 2011; Von Ah & Kang, 2008). In addition, also consistent with the wider literature, study participants with lymphoedema reported lost physical ability in the arm on the affected side post-operatively and experienced an understanding that lymphoedema would be a long term after effect (Albert et al., 2006; Engel et al., 2003; Karki et al., 2005).

Coping with breast cancer treatment is reported as a physically and psychologically distressing event in both quantitative (Ando, N., et al., 2011; Carver et al., 1993a; McCorry et al., 2013), and qualitative studies (Boykoff et al., 2009; Cebeci et al., 2011; Drageset et al., 2011). However, an interesting finding related to the physical dimension in this study was a newfound appreciation described by four out of the ten participants about how well their bodies coped and managed to heal and recover. For example, Debbie rated her chemotherapy overall as a successful event because it reduced her tumour size, and she shared how the chemotherapy treatment itself was not as bad as she had imagined it would be. Yet simultaneously, Debbie also reported negative experiences resulting from chemotherapy, such as alopecia. This is consistent with Brunet et al. (2013) who showed that women can have both positive and negative embodied experiences after breast cancer. Coping by looking at positive aspects of experience could be seen as positive reframing or looking for the silver lining as in benefit finding (Tennen & Affleck, 1999) by putting the past into perspective. However, it could also be explained by the concept of illusions outlined by Taylor et al. (1984) in the Theory of Cognitive Adaptation understanding coping by positively reinterpreting reality. An existential perspective might see it as an example of Debbie coping by exercising her freedom to choose to focus on and remember the positive outcomes rather than ruminate on the negative ones, as she faced the given limits of her situation (Frankl, 2010; Langle, 2003; Vos, Joël, 2015b).

A phenomenological existential approach could help women explore their experience of embodiment, particularly about beliefs and values concerning cultural ideas of beauty and

femininity, to allow them to understand their distress better. A collaborative exploration with clients could focus on how she sees herself now compared to before cancer treatment. Prompts such as: What is it like to have a changed body? What do the changes in her body mean for her sense of identity? What does her changed body mean for her relationship with her intimate partner and the wider world? An existentially attuned psychologist will listen closely to see if the client holds sedimented beliefs about her body image. Such ideas are likely to impact upon her worldview and inform how she copes with life. Engaging with the client on an embodied phenomenological level could help them learn more about how they see themselves, foster self-compassion, and cope with their dilemmas of embodiment.

ii) The intersection of Coping and Economic Privilege. The participants each had access to stable housing, employment opportunities, food, water, electricity, telephones, computers, internet, and public and private health care access. Economic privilege impacted their lived experience of coping in positive ways because it afforded them options and choices, which added to their sense of control as they faced an uncertain situation. For example, all participants had opportunities to take time off work during and after cancer treatment, affording them time to adjust to their changed bodies and recuperate without coping with the burden of worry about financial instability. The participants also had the means and personal resources to use problem-focused coping strategies such as seeking professional help like private psychotherapy, specialist lymphoedema massage and complementary healing therapies. However, their socioeconomic privilege had limits; it did not prevent nor negate the need to cope with physical and psychological suffering related to treatment for primary breast cancer.

Debbie's situation illustrates one example; after reconstruction surgery, her donor site wound would not heal, and she had to manage daily wound care for three months after surgery.

Debbie lived in relative comfort in her own home and had the means to source dressing supplies and maintain a clean environment to prevent infection. Even though Debbie managed to cope, evidenced by the fact the wound eventually healed, she reported this as a traumatic event. Debbie

was left to cope with feelings of guilt, holding personal responsibility for the resulting scar tissue, a permanent reminder of her cancer. Debbie also wonders if it is standard practice to expect individuals to care for complex post-surgical wounds in the community or if she had somehow been overlooked in the system. This case raises questions about how this same scenario could be for other women with fewer privileges, such as homeless women or those housed in temporary or shared accommodations. Such women might not have the funds to afford to buy dressing supplies or find a private, clean space to manage wound care. It also raises questions about access to community support services for wound care for women after breast cancer surgery. In addition to practical concerns, it would also be helpful to learn more about the psychological impact and potential trauma outcomes for women tasked with managing their post-mastectomy and reconstruction surgery wound care. This knowledge could assist psychologists and psychotherapists in selecting appropriate therapeutic modalities like trauma-informed approaches. Medical professionals could also benefit, particularly cancer nurse specialists (CNS), who directly contact patients in the early stages of treatment and recovery and are key to sign-posting patients to appropriate services. Perceived trauma is an important area for further investigation because research has suggested that women with breast cancer are at higher risk for post-traumatic stress symptom burden; however, few meet the criteria to be diagnosed with PTSD (Voigt et al., 2017). More research could expand on this finding to find answers to the question; if a woman of means reported feeling traumatized by coping with managing her wound care, what might this mean for a woman with many more challenges of living related to socioeconomic disparities?

The finding linking coping resources to socioeconomic privilege raises questions about how women with breast cancer in the UK cope with these same challenges who might not have economic stability. In a Polish study evaluating socioeconomic variables on coping strategies, pain management, disease acceptance and adjustment to breast cancer, Czerw et al. (2015) concluded that the level of disease acceptance is positively correlated with the individual's income, the higher the income the greater acceptance of illness.

iii) Implications for Social Justice and Health Inequalities. Coping with the burden of breast cancer holds implications related to social justice and health inequalities. An example relating coping resources to privilege is evidenced by the fact that all the participants in this study had choices and options about continuing their employment. Most had sick leave benefits or private funds to allow them to take time off work to focus on their physical recovery. Women in lower socioeconomic groups might not have access to jobs that offer such benefits. They might have had to cope with returning to work long before they were fit and able just to meet basic survival needs. Many other questions arise about women such as refugees or those who have entered the UK undocumented who might not be eligible for social service benefits such as housing. Not having a permanent physical address has consequences for accessing medical services; proof of identity and address are needed to register with a GP in the UK. If women are not in the system, they will not get invited to attend routine mammography screening, increasing the risk of being diagnosed with breast cancer much later in the disease process when it may no longer be curable. Research on social inequalities and cancer shows that cancer incidence and cancer survival are related to socioeconomic factors (Kogevinas et al., 2006; Vaccarella et al., 2018). More specific research related to coping with breast cancer and social inequalities is offered by Clark (2005) who studied how class-based inequalities impacted the ways women use the coping strategy of seeking information. She found that middleclass women have more resources to seek and interpret information on their own and be more assertive with their medical team while working-class women are more likely to rely on trusting medical relationships and be subjected to medical paternalism.

Counselling psychologists need to think about the implications of health inequalities and social justice. It is essential to remain cognizant of the broader context of clients' experiences to understand the extent of coping across their wider worldviews. It is vital to avoid making causative assumptions about what brings clients to psychotherapy, such as low mood related to breast cancer. A sombre mood might be related to breast cancer, but the experience of low mood might also hold an entirely different meaning for the individual. Irene's example of going to psychotherapy and

asking, "how crap does your life have to be when having breast cancer is third on your list?" illustrates this point. Irene was trying to cope with a breast cancer diagnosis while also facing bereavement and the end of her marriage simultaneously. This narrative is one example of the complexities of living that might be encountered by psychologists during psychotherapeutic work with clients living with cancer.

### 5.1.4 Discussion of Findings in the Personal Dimension

Within the framework of the four dimensions, the personal world is concerned with identity and establishing a coherent sense of self. Questions relating to identity are always playing out because the self is not a fixed entity and constantly changes in relation to the outside world (van Deurzen, 2010). The existential givens include ideas such as freedom to choose, uncertainty, interpersonal relationships, values, tensions between polarities, time and temporality, and existential anxiety (Strasser & Strasser, 1997). The concept of liminality from an existential perspective holds that ambiguity and uncertainty are normal states of human existence (Little et al., 1998). The findings related to the personal world revealed how the participants coped with the psychological repercussions associated with existential givens in the short and longer terms, particularly existential anxiety related to fear of cancer recurrence and the experience of dealing with an altered sense of self.

i) Coping with Psychological Repercussions of Existential Distress. The most important finding related to coping with short-term psychological repercussions raises questions about the ability to think clearly when under extreme stress. The initial shock and resulting negative psychological repercussions such as fear and worry were challenging for all participants, as they struggled to understand the meaning of breast cancer and the implications of this diagnosis on their future health and well-being. This finding is consistent with other studies that report existential distress when women are first diagnosed with breast cancer (Blow et al., 2011; Curtis et al., 2014; Drageset et al., 2010; Kenne Sarenmalm et al., 2009; Tighe et al., 2011; Vehling & Kissane, 2018). At

this point, the stressful time shortly after diagnosis, while still reeling in shock, study participants were expected to make important choices about their treatment and surgical options. This situation is echoed by Blow et al. (2011) who reported how women in their study felt overwhelmed while making treatment decisions related to chemotherapy. Although such decisions often are medically necessary, particularly for time-sensitive treatment, this situation is far from ideal and has implications for future psychological distress.

Coping with the Existential Given of Choice and Responsibility. All participants had to sit with the knowledge that they had the freedom to choose to accept the treatments offered to them by the medical professionals. Still, they also had to take responsibility for the choices they made. All participants in the study were initially compliant with the treatment plans offered to them. This finding is interpreted as a type of problem-solving coping strategy, in that the surgery, chemotherapy and radiotherapy were agents and processes to rid the participants of cancer. Coping by compliance with medical treatment strategies was viewed as a solution to the problem of breast cancer. Coping with taking responsibility for choices made about specific treatment options was a more complicated matter. For example, Jean and Debbie blamed themselves for the outcomes of their surgical choices, expressing regrets about the types of reconstruction surgery they elected to have. They are living with persistent feelings of self-blame and guilt resulting from their choices. Both believed that reconstruction surgery using their body tissue was a more natural option than having a prosthetic breast implant. However, neither reported that they were fully prepared for the long-term consequences of these surgeries, leaving them to cope with iatrogenic trauma and experiences of loss in work and leisure activities. Having to cope with iatrogenic trauma and disability is consistent with findings reported by Karki et al. (2005), who studied the impact of breast cancer treatment and impairments of the upper body and limbs and how these restricted participants' activities six and twelve months after breast cancer surgery. They concluded that many women abandoned their leisure activities and reported that their ability to work had decreased,

recommending an urgent need for developing rehabilitation protocols for breast cancer patients (Karki et al., 2005).

Remorse or regret over treatment decisions in the cancer literature presents mixed findings. Some view treatment regrets as a factor in cancer-related distress (Advani et al., 2019; Connolly & Reb, 2005), while others found that few women experienced regret after their breast cancer treatment decisions (Martinez et al., 2015). This study offers a novel view of decision regret, situating it as an element of coping with the existential given of taking responsibility for choices. Heather faced the existential givens of choice and the inevitable responsibility for her choices when she decided to stop chemotherapy against the advice of the oncology team because she believed the treatment might kill her before cancer did. Heather coped with her death anxiety by assessing the level of threat she was experiencing physically and decided to take control of what she could. Heather was uncertain if she would die from breast cancer, but she felt sure at the time that she would die from the side effects of chemotherapy because of her embodied experience of the limits of her body. This finding is important because refusing recommended treatment is a dilemma that initiates patient referrals to psychological therapies. Therefore, psychologists working with oncology teams need personal insight and awareness about their existential anxiety to be capable of holding their biases aside. Only then can they provide a safe therapeutic space for clients like Heather to explore the personal meanings related to difficult decisions about treatment options that could have life or death consequences for them.

Coping with Existential Anxiety related to Fear of Cancer Recurrence (FCR). Fear of recurrence of breast cancer was the most prevalent psychological longer-term repercussion for all participants in the study, which is consistent with quantitative (Mutsaers et al., 2016; Simard et al., 2013) and qualitative literature (Drageset et al., 2015; Kvale et al., 2015). However, this study adds qualitative knowledge by adding evidence to confirm the relationship between existential anxiety and FCR. Existential anxiety appears to be at the root of the FCR because it concerns living with a heightened awareness of the threat of death (Mutsaers et al., 2016), which is ambiguous. After all,

no one can be certain when they will die, but for the participants in this study the threat of disease recurrence remains a real possibility, so their fears are rational not neurotic. The study participants shared how they experienced fear of recurrence as anxious thoughts that they mainly managed to hold out of conscious awareness by avoidance, but how fear and anxiety returned at times of increased stress, such as anticipating check-ups and waiting for results. At these times, participants like Beth accepted that they would have a tough week and tried not to worry. Beth's example of trying not to worry is an example of cognitive reframing and avoidance by distracting herself. Beth felt relief once she got news of results showing no evidence of disease, allowing her anxiety to retreat again. These findings are consistent with Sharpe et al. (2018). They studied the relationship between death anxiety and fear of recurrence, rating this as one of cancer survivors' most prevalent problems and unmet needs. They suggest that predictions of terror management theory (Pyszczynski et al., 1999) have important clinical implications for existential meaning-focused approaches to therapy (Breitbart, William et al., 2015) with the observation:

"At times when mortality is most salient (e.g., diagnosis of cancer; diagnosis of recurrence; prior to routine testing), individuals are likely to have thoughts of their own death and to use largely avoidant strategies in an attempt to minimize the associated death anxiety. However, as these imminent threats pass (e.g., end of treatment; reassuring test results), mortality salience is likely to diminish and individuals are likely to be more amenable to the types of distal defence strategies that minimize death anxiety, such as meaning-making, re-evaluation of values, and priorities and bolstering self-esteem" (Sharpe et al., 2018, p.2562).

The findings of this study support this statement and provide qualitative evidence for the relationship between death anxiety and FCR, a literature gap identified by Sharpe et al. (2018). Still, I prefer not to label meaning-making activities like reviewing values, realigning priorities, and self-care to boost self-esteem with the psychodynamic language of defence strategies but instead simply

interpret them as ways of coping that are meaning-focused. However, terms such as proximal and distal defences are part of the psychodynamic language used in Terror Management Theory (TMT), which proposes that humans cope with the awareness of inevitable death, experienced as existential anxiety, by their constructions of worldview and sense of self (Greenberg et al., 2004; Pyszczynski et al., 1999). TMT is helpful because it offers a theoretical understanding of coping with existential concerns and the limits of life.

ii) Coping with an Altered Sense of Self. The study participants coped with psychological adjustment to an altered embodied sense of self as they faced distress related to changed body image and feminine identity and changes in their worldviews after breast cancer. Participants shared how they coped by realigning their values and focusing on different meanings as they tried to accept the changes they faced. These findings are consistent with other studies that acknowledge how the experience of breast cancer treatment can affect identity and cause psychological distress (Brunet et al., 2013; Curtis et al., 2014; Tighe et al., 2011). In addition, biographical disruption and liminality are helpful terms to describe states of ambiguity and uncertainty that participants experienced as they tried to come to terms with the meanings connected to their altered bodies and sense of self (Koutri & Avdi, 2016; Liamputtong & Suwankhong, 2015; Thomas-MacLean, 2004; Trusson et al., 2016). The notion of a self that is not fixed underpins the existential position on identity and selfhood, and this provides a theoretical explanation to help understand how people can cope with change and reinvent themselves throughout life.

Questions about the potential for unintentional psychological trauma during medical procedures are raised by Beth's experience, who described feeling disconnected from her body during her cancer treatment, which impacted her sense of self. Her narrative account of viewing herself as an object could be interpreted as a trauma response. Beth needed to separate her feminine sense of self from her embodiment as she endured treatments that left her feeling that she had given her body over to others who owned her body while they fixed it. Beth shared how she coped with feeling disconnected by retaking ownership of her body with the help of complementary

therapies such as massage. This finding supports access to complementary therapies for women after breast cancer treatment, but it also highlights the psychological risks of exposing the body during medical procedures. Exposing private body parts could hold significant implications for women with personal histories of childhood sexual abuse to recall traumatic memories during breast cancer treatment. Childhood sexual abuse remains taboo even though an estimated one in five women report physical abuse. These risks have prompted critical UK studies led by clinical psychologists researching the relationship between childhood abuse and adult attachment styles, concluding that the damaging effects of childhood abuse on adult relationships can also extend to relationships with surgeons in cancer care (Clark et al., 2011). In another study, researchers investigated whether clinical staff should ask breast cancer survivors about their abuse histories. They found that women with personal histories of sexual abuse would benefit from being given a choice and opportunity to disclose abuse during assessment by staff trained to manage such disclosures and provide supportive therapy (Clark et al., 2014).

Most participants in the study struggled to come to terms with their changed physical appearances that did not align with their sense of still being themselves. These conflicting views about an altered sense of self and changed worldviews held psychological implications for participants who had to cope with feelings of shame, embarrassment, and self-consciousness when being seen by others. An existential understanding of this phenomenon can be found in Sartre's three orders of the body, outlining how people can feel embarrassed or self-conscious when they experience their body in the way they imagine others experience it (Carel, 2016; Sartre, 1943). The study participants coped in different ways with this dilemma; some used problem-solving approaches doing what they could to improve their perception of how they looked, while others reviewed priorities and decided that looks no longer mattered in the grand scheme of life. For example, Emma was unhappy with weight gain and coped by reframing her views, sharing her new belief that being alive is more important than being thin. Clinicians need to consider the complexity of clients' coping strategies; using positive thinking to reduce tension might only be a temporary

solution that will not address or alleviate deeper-rooted feelings of shame. These findings support existing literature linking emotional distress to changed bodies. For example, Brunet et al. (2013) found that women in their study reported intense thoughts and emotions about their changed bodies, particularly weight gain, since women in Western society are valued based on physical appearance. They suggest that women might also have internalized weight-based stereotypes holding them responsible for their weight. Other studies point to the potential for existential distress in cancer (Vehling & Kissane, 2018) and support the need for more research on this subject, particularly the provision of existentially informed therapies.

Contrary to findings that link an altered sense of self to existential distress, two participants in this study had different experiences. The first was new levels of respect for their bodies after their illness, recognizing the resilience of their bodies, and the second was newfound courage and self-confidence. In the first example, Fay reflected on how her relationship with her body had improved and how she is now more attuned to it. Yet, she also copes with feeling responsible for her past when she was less attuned and did not notice her body as acutely as she does now, wondering if her breast cancer experience might have been different if she had been more in tune with her body. Fay now prioritizes her time to exercise and eating well, focusing more on self-care. This finding is significant as it supports access to programs after breast cancer surgery encouraging physical fitness and weight management for health. In addition, studies have shown a link between obesity in postmenopausal women and an increased risk of developing breast cancer (Munsell et al., 2014).

Unlike others who reported diminished self-confidence, Heather experienced the opposite effect and emerged from being a shy and reluctant person who is now more courageous and willing to try new things. Heather had intentionally lost a significant amount of body weight before her breast cancer diagnosis, so she had been positively experiencing the gaze of others by receiving encouragement and positive feedback from her weight loss group. Breast cancer made her acutely aware of her mortality, which positively impacted her worldview. These findings highlight how some women will cope well; they find benefits in their cancer experience and feel more resilient after the

experience. These two examples of transforming traumatic experiences into positive ones could be understood as post-traumatic growth (PTG) or resilient coping. PTG literature shows that although breast cancer can be distressing, it also holds potential for positive experiences too (Drageset et al., 2015; Folkman, 2008; Silva et al., 2012; Wang et al., 2014).

The findings in the personal dimension highlight the existential nature of the psychological distress and liminality that the participants faced as they experienced an altered sense of self. An existential-phenomenological clinical approach could benefit women with breast cancer struggling to cope with psychological repercussions. A focus on finding meaning and a deeper understanding of experiences of illness and recovery could be achieved by fostering self-compassion by inviting them to think about their strengths and limitations (van Deurzen & Arnold-Baker, 2005).

# 5.1.5 Coping in the Social Dimension

Three themes emerged in the social dimension; the first was how participants coped by finding meaning in care, the second disclosed coping by finding meaning related to work, and the third revealed the need to manage ambiguity and meaning encountered in the gaze of the other. Sartre (1943) offers a philosophical discourse on the gaze of the other, describing how humans experience this gaze indirectly through feelings of shame when we realize others are observing us and how this type of shame can turn to fear when we feel threatened by the judgements of others. Heidegger (1962) used the terms' Being-in-the-world' and 'Being-in-the-world-with-others' to describe how humans are always situated within, interconnected, and in relation to other people and things in the world around us. In the context of this study, the participants' diagnosis of breast cancer forced them to traverse the unfamiliar terrain of the medical world. The social world revolves around the human need to belong in a community and be in relationships with others, acknowledged and accepted. Yalom (1980) lists isolation as one of the four fundamental existential concerns that give rise to existential anxiety. It is vital to consider the potential for loss within the

experience of illness as described by Toombs (1987) and how such losses could disrupt the social dimension, having implications for existential anxiety.

i) Meaning in Care. The findings showed how each participant found meaning in their relationships with others. They described how they coped with their cancer by caring for others and by accepting being cared for, particularly the importance of meaning related to care within medical relationships. Yet paradoxically participants also faced the loss of relationships that left them to cope with an additional burden of rejection and abandonment. These findings are consistent with studies that point to the importance of social support networks for women with breast cancer (Drageset et al., 2011; Dukes Holland & Holahan, 2003; Gremore et al., 2011; Mallinckrodt et al., 2012).

Being cared for is a basic human need; however, the novel finding in this study showed differences between wanting to be 'cared about' and 'needing to be cared for'. The cultural ideals shared by the study participants, such as valuing autonomy, self-efficacy, and personal agency, were challenged as they struggled to adjust to the limits of illness. Jean's narrative provides the best example of this paradox. Jean shared her history of loss and disrupted attachments and how her identity as a health professional sedimented her belief that instead of being cared for, she should be caring for others. When her friends learned of her breast cancer, she could not tolerate their sympathy and well-meaning concern. Jean coped by isolating herself socially from others. She solved the problem of communicating updates about her progress by turning to social media, where she could manage by controlling the content and contact she had with others. Jean wanted others to care about her, but she could not tolerate seeing them cry, as this triggered difficult emotions for her, like anger; she tried to make sense of their tears, wondering why they were crying when she was the one with cancer. Although it made sense at the time for Jean to cope by isolating herself, this strategy also held the implication of existential anxiety related to isolation and not being part of her social group. An existential approach to psychotherapy could be helpful in this situation to allow Jean to explore the broader meanings behind her discomfort and anger in response to the tears of

others and discover how her rules about closeness or distance from others could be regulated (van Deurzen & Arnold-Baker, 2005, p.90).

Seeking Peer Support. Study participants reported the pros and cons of support groups.

Most felt cared for by attending peer support groups both in-person and online. Primary occult breast cancer, a rare form of the disease, left Heather searching for others to connect with who shared her diagnosis. Social media provided Heather with the means to access other women located across the UK who she might not have met without this form of communication. Together they coped by sharing their stories, and this type of peer support helped Heather cope with feelings of isolation and difference. Although peer support was meaningful and helpful for most participants, Fay and Allison reported the drawbacks of turning to other breast cancer survivors for help. Allison pointed to the problem of potentially being emotionally overwhelmed by hearing about the experiences of others. Fay shared her experience of being objectified when used as a worst-case example. She resented others who used her situation to reframe their perception and express gratitude that they were not as severely affected as she was, leaving Fay to cope with feelings of anger and despair. These findings are significant because most women with breast cancer are offered group support through cancer charities and hospital settings.

Group therapy rates as the gold standard psychological support for women with breast cancer (Guarino et al., 2020) with positive outcomes for research on many different approaches, for example, video-conference versus face-to-face delivery of group services (Lleras de Frutos et al., 2020), CBT nurse-led groups for hot flushes and night sweats in women with breast cancer (Fenlon et al., 2020), the efficacy of group logotherapy on decreasing anxiety in women with breast cancer (Mohabbat-Bahar et al., 2014). However, contrary to many positive results, Boesen et al. (2011) reported that psychoeducation and group therapy did not decrease psychological distress, increase the quality of life, mental adjustment, or improve marital relationships for women with primary breast cancer. Although groups can benefit many women with breast cancer, I believe that access to individual psychological support might be a more appropriate intervention for certain people. For

instance, people who use disengagement coping, avoidance, and denial, are more likely to have cancer-related distress (Langford et al., 2017). Psychological assessment and screening tools such as the cancer coping questionnaire (Greer & Moorey, 2011) could help evaluate individuals' coping strategies and resources as part of the treatment plan and care pathway. Assessment of coping styles could help triage and get women most likely to need individual psychotherapy access to the most appropriate psychological support in a timely fashion.

Caring for Others to Maintain Identity. Caring for others was a strategy study participants used to adjust to an altered sense of self. The literature on women and caregiving support this finding, confirming caring as an influential factor of socially constructed self-identity (MacRae, 1995). Debbie found meaning in caring for her family and friends during her cancer experience by cooking for them, reporting how it helped her manage her stress and feel normal. Cooking was her unique coping method because it connected her to her former sense of self and supported her identity as the nurturer in her family.

The Paradox of Care. Care appears to have both positive and negative qualities. On the one hand, care can provide a sense of purpose, meaning, and connection to the social world while also being challenging and stressful, leaving women to find the balance between caring for others and caring for themselves (DiGiacomo et al., 2011; Mackenzie, 2014). On the other hand, coping with breast cancer forced Allison to recognize her need to realign her priorities and put herself first instead of caring and doing for others. Allison shared how she coped by engaging in individual psychotherapy, where she learned to set boundaries that have empowered her to be more selective about her choices relating to with whom she shares her time and energy. Van Deurzen and Arnold-Baker (2005, p.90) offer an existential clinical approach to this dilemma, suggesting that clients can work towards a goal of being "capable of holding one's own in relation to others...not to be bullied or dominated by others but keep them in their place and take up our own rightful place amongst all the others in the world". The clinical implications for psychologists working with women with breast cancer include the need to help individuals explore both the broader meaning of women's roles and

how these ideas might fit in with their unique personal worldviews. In addition, psychotherapy can empower women to be more assertive in getting their needs met while being mindful and respectful of cultural differences that govern individuals' beliefs and values.

Relationships with Medical Staff. Medical relationships took on special meaning for participants who coped by trusting strangers, the medical experts, who had access to their bodies in matters of life and death. Participants coped by ceding control while taking a leap of faith, trusting the process, and hoping that the abilities of others would restore them to health. Folkman (1984, p.844) described this type of coping as emotion-focused coping in the form of vicarious control. In this case, the study participants ceded their control to powerful others, the medics, and by trusting them and the treatment process, they could tolerate the uncertainty of cancer treatment. The value of these relationships and the potential for dependence on alliances between participants and the oncology team were most visible at the end of treatment when participants were discharged from services. Some participants felt lost and abandoned at this specific time and had to seek further psychological support. This finding is consistent with other studies that identify adjustment difficulties at the end of breast cancer treatment (Lethborg & Kissane, 2003; Powers et al., 2016) and implications of attachment style for clinical relationships (Clark et al., 2011). In addition, the experiences of study participants point to the importance of the timing of support services, suggesting a need for assessing the level of dependence and attachment individuals have formed with their medical teams that could help with discharge planning referrals to aftercare resources.

ii) Meaning in Work. The findings highlighted the interrelated meanings that everyday activities like work held for participants and how all participants experienced a change in meaning related to work. For Allison, work was an enjoyable experience and a way to cope; it was a distraction that allowed her to avoid thinking about breast cancer and provided a link to her former sense of self. This finding is comparable with other literature that views work life as a way of feeling healthy and returning to normal (Drageset et al., 2010; Johnsson et al., 2010; Tiedtke et al., 2010) and as a way to manage emotions and feel in control of life (Drageset et al., 2015b).

Others found new meaning in their work lives, such as Beth, who saw her work as a legacy, a way to boost her sense of self-worth and satisfy altruistic desires to give back to other cancer patients in her holistic therapy practice. This example supports the notion of the transformative nature of breast cancer (Smit et al., 2019).

Work lost meaning for Debbie, Cindy, and Gail. They each coped by stopping work and turning their attention to other things that were more important by realigning their priorities after facing serious illness. This finding links meaning in work to a confrontation with existential givens, particularly existential anxiety related to an altered sense of self. The phenomenon of changed meaning in work is present in other studies (Drageset et al., 2015; Drageset et al., 2020; Johnsson et al., 2010; Tiedtke et al., 2010). MacLennan et al. (2021) describe the theme 'changing meaning in work' in existential terms related to interpersonal relationships and selfhood issues. Their IPA study on the meaning of work for professional women living with breast cancer resonates with my findings linking meaning in work to confrontations with existential givens and an altered sense of self. One of the limits of both studies is that the samples consisted of women from higher socioeconomic brackets. MacLennan et al. (2021) recruited professional women for their research and recommended further research to explore the specific experiences of women who do not work in professional roles. The selection criteria for my study did not include a focus on employment. However, it is a thought-provoking coincidence that both samples recruited participants with socioeconomic privileges, raising the question of what types of women with breast cancer want to volunteer to participate in research studies.

iii) Coping with Ambiguity in the Gaze of Others. Within the social dimension, participants shared how they had to cope with ambiguity related to how they felt in themselves compared to how other people saw them and cope with the fact that they cared about or had an emotional response to what other people thought. The reader can further understand these novel findings in terms of existential philosophy. Heidegger (1927, 1962) extends the concept of 'Being-in-the-world-with-others' to include solicitude. This care or concern for others and what other people think of us

is an essential part of being human and helps us understand why caring and worrying are inescapable givens of existence. Solicitude can help us better understand the study participants' experiences coping with ambiguity in relating to others. For example, Jean spoke about feeling upset and embarrassed when her friends tried to help her. They were caring for Jean in a way that left her feeling invalidated as a person. Jean experienced care as pity, and this left her feeling shame. Jean now faced a dilemma. She wanted to return to her social life and the things that brought her joy, yet she could not cope with the reality that others thought she needed help. Jean's shame can also be interpreted by Sartre's (1943) view of the gaze of others focusing on experiences of fear of judgement.

Gail also suffered, yet her experience was the opposite of Jeans. Gail contended with other people who coped with their own distress by focusing on the positive in her situation. When diagnosed with breast cancer, Gail felt physically fit, healthy, and terrified that she might die. Gail might have looked fine, but she did not feel okay. Gail also experienced guilt and shame, imagining that others might see her as a failure for not being emotionally strong because she had been a nurse. This finding is important because it highlights the potential for complex distress in nurses with breast cancer. Research studies on health care professionals report a specific type of distress called 'insider vulnerability' (Mapi, 2018; Vachon, 2006) activated due to their extensive understanding of the illness and treatment.

Existential psychotherapy could benefit clients facing the ambiguity that occurs in interpersonal relationships. Spinelli (2007) describes two clinical therapeutic stances, 'being-with' and 'being-for' clients. These are ways to accompany clients as they explore their unique worldview, focusing on meanings and values concerning their narratives and dilemmas. 'Being-for' clients does not mean that therapists hold goals of trying to help or change them, but instead, it is about acknowledging that the views held by the client are true for them. After clients become more aware of their expectations and assumptions, they have an opportunity to reflect upon their beliefs and values and adjust their worldview as they deem fit.

## 5.1.6 Discussion of the Search for Meaning and the Spiritual Dimension

The literature on the role of spirituality in coping offers diverse concepts and findings (Ahmadi et al., 2017; Gall et al., 2005; Mesquita et al., 2017; Park, C. L., 2010; Park, C. L., 2013; Swinton et al., 2011; Taylor, E., 2003; Visser et al., 2010). However, the lack of consistency in definitions and confusion between religion and spirituality in methodologies has drawn criticism (Swinton et al., 2011), specifically that the concept of spirituality does not help understand coping with existential distress (Salander, 2018). Considering this criticism, Swinton et al. (2011) acknowledge the difficulties in finding a narrow definition for spirituality and instead offer a perspective described as a "quest for meaning, value and relationship with Self, others and, for some, with God" (2011 p.644). They grounded their study on the role of spirituality during early breast cancer in the theoretical existential philosophy of Frankl (1969) focusing on spirituality as a search for meaning, in conjunction with Hays's understanding of spirituality as relational consciousness (2006). Relational consciousness is an awareness of being in a relationship with all of reality, be it other people, one's sense of self, the environment or religious beliefs about God or a higher power (Hay & Nye, 2006; Hay, 2006).

The recognition of interconnectivity with others and the search for meaning are helpful theoretical viewpoints to conceptualize the spiritual nature of being human. They align with the Four Worlds model, which is also grounded in the notion of interconnectedness across physical, personal, social, and spiritual realms of experience. Van Deurzen and Arnold-Baker (2005, p.217-219) explain how the spiritual dimension enables people to make sense of life to create personal meaning. They acknowledge that humans can have a relationship with the unknown at the metaphysical level of existence, holding that each person has unique perspectives on life and that organized religion is not obligatory.

The novel findings of this study support the view that spirituality and spiritual beliefs are related to coping with existential concerns, particularly death anxiety. The results also add evidence

to the concept of relational consciousness, illustrated by the role of complementary therapies in spiritual support. Thirdly, the findings add to the knowledge of the utility of meaning-focused coping strategies to make sense of life. Finally, these novel descriptions of the participants' experience of their spiritual world views add to the understanding of complex phenomena in the spiritual dimension of life.

i) Spiritual Beliefs Eased Death Anxiety. None of the study participants was formally affiliated with organized religions but held secular views on spirituality. Each had various personal spiritual connections; some found spiritual solace in nature which is consistent with the concept of sanctification of nature (Ahmadi & Ahmadi, 2015). Others believed in something greater than themselves or the possibility of life after death, even though they had no solid religious affiliations. For example, rituals like lighting candles and praying helped one participant feel connected to her deceased mother, while another participant believed in communicating with dead relatives by visiting spiritualists. These behavioural examples show how the participants used continuing spiritual bonds (Klass, 1996; Stroebe et al., 2010) to maintain a sense of still being connected to their deceased family members. It is this connection that helped them to cope with existential anxiety and be less afraid of dying. However, some participants in the study shared how they experienced a crisis in faith and felt disconnected from their sense of spirituality, leaving them in a crisis of meaninglessness. The participants who struggled with meaninglessness in the spiritual dimension reported not coping well with existential distress, notably voicing fears related to dying from disease recurrence. This finding shed light on how the relationship between loss of meaning and existential distress was experienced and adds to the knowledge of how cancer patients might cope with the duality between meaning and existential givens.

ii) Spiritual Support in Complementary Therapies. Study participants turned to meditation practices and complementary therapies such as Reiki to cope with and soothe their anxiety. They reported how this helped them reconnect to their embodied selves after medical trauma. This need to be connected to the sense of self can be understood as a spiritual concern using the concept of

relational consciousness (Hay, 2006). Cancer charities and hospitals in the UK provide holistic biopsychosocial models of care for all cancer patients, offering a wide range of evidence-based complementary therapies (CT). Examples include but are not limited to massage, aromatherapy, and acupuncture. In addition, energy healing therapies such as Reiki are considered complementary spiritual therapies. Although complementary spiritual therapies are difficult to evaluate, it is recognized that the placebo effect outweighs potential harm, so they have been accepted by the medical community (Saad et al., 2017; Sulmasy, 2002). A comprehensive guide to complementary and alternative therapies, along with evidence-based research related to them, is available online at the Cancer Research UK website (Cancer Research, U. K.). The use of complementary therapy (CT) by breast cancer survivors in the literature highlights the relationship between CT and a sense of control gained by women breast cancer survivors who view engagement with CT as taking an active role in their cancer recovery (Hann et al., 2005). Other studies suggest that women with breast cancer who engage in CT are more likely to report symptoms of depression and anxiety related to fear of cancer recurrence (FCR) (Burstein et al., 1999; Digianni et al., 2003) and this is consistent with the findings of this study since all the participants reported FCR.

Several participants reported attending meditation courses offered by cancer charities and local Buddhist communities. Interventions such as mindfulness meditation helped some participants cope with FCR and existential givens, such as being in stressful interpersonal relationships. In contrast, others found such techniques challenging to master and unhelpful. According to Payne (2011), mindfulness-based interventions are helpful for all cancer patients at any stage of the disease if they are cognitively intact. Psychological treatment modalities, including third-wave CBT, emphasize mindfulness, emotions, relationship, values, goals and acceptance. Examples are mindfulness-based cognitive therapy (MBCT), acceptance and commitment therapy (ACT) and dialectical behavioural therapy (DBT), to name a few (Hayes & Hofmann, 2017). Claims suggest mindfulness approaches are well suited for integration with existential therapy (Harris, W., 2013). However, more recent studies have revealed concerns and challenges about mindfulness and

meditation research (Davidson & Dahl, 2018; Van Dam et al., 2018). Van Dam et al. (2018) point to the potential for misinformation from previous studies that might lead public consumers to be harmed, misled, and disappointed. Davidson and Dahl (2018) remind readers that contemplative practices and mindfulness, adapted from spiritual traditions, were not originally developed to treat disease. They question the efficacy of such approaches with vulnerable persons with physical and psychological health challenges. The findings of this study offer support for both positions; meditation practices were helpful as a coping resource for some participants, while for others, it was not a good fit.

Complementary therapy is accredited in the literature as a strategy to reduce stress and has the potential for therapeutic benefits such as symptom relief and improvement in the immune system (Abrahão et al., 2019; Kang et al., 2011; Ventola, 2010). The findings of this study reveal how participants engaged in mind-body interventions such as meditation and prayer, body-based methods such as massage and energy therapies like Reiki to help them better cope with their physical and psychological cancer-related stress.

iii) Meaning-focused Coping to Make Sense Out of Life. Meaning-focused coping strategies were used by all participants, particularly realigning priorities, benefit finding, finding meaning in ordinary events and meaning attached to legacy. Theoretical coping literature supports these findings, including the transactional model of coping (Park & Folkman, 1997), meaning-focused coping (Folkman & Moskowitz, 2000; Folkman & Moskowitz, 2007), the meaning-making model for understanding meaning, spirituality, and stress-related growth (Park, 2010; Park, 2013), and the existential coping strategies outlined by Ahmadi (2006) in her study on spirituality and coping for cancer survivors.

Coping by realigning priorities. Realigning priorities included making more time for self-care by adjusting work schedules and setting personal boundaries. Participants coped by putting their own needs first; however, this sometimes left them to manage feelings of guilt and shame. In addition, untangling the meaning within the multitude of roles women face holds implications for

prioritizing self because of the sense of responsibility linked to the potential loss others might experience. For example, Emma had conflicting views about the meaning of her work ethic.

On the one hand, she had a sense of duty, a moral value of helping others first, against her self-worth and need for physical well-being to do her job. On the other hand, she struggled to come to terms with her need to take time off work to look after herself before returning to help others, expressing concerns about letting down her work colleagues. These findings add to the knowledge base by pointing to the complexity and paradoxes of realigning priorities for study participants.

breast cancer diagnosis led participants to cope by assigning new meanings and living more purposefully. For example, Gail shared how she feels stronger and more assertive since having breast cancer. Others like Beth and Allison connected with a sense of courage. Beth took a risk to use her voice to help other women facing breast cancer, taking social action by offering a podcast about the benefits of complementary therapies. Allison shared how she was glad that she dared to seek psychological support as she overcame negative cultural biases linking the need for support to weakness. Fay reflected on her changed attitude and lives her life more purposefully, recognizing her resilience after cancer and how she feels able to cope with anything now. The term benefit finding is also referred to as posttraumatic growth and stress-related growth in the literature (Park, 2013; Sumalla et al., 2009) and is the experience of positive psychological growth after a traumatic event (Manne et al., 2004; Park, 2013; Sumalla et al., 2009; Tedeschi & Calhoun, 1995). The study findings add to this literature by illustrating the rich diversity of perceived benefits of lived experiences of study participants.

Finding meaning in ordinary events. Feeding the soul was the term used by Heather, who found new meaning while engaging in social activities like singing and running. These examples are consistent with the literature on the global health benefits of singing (Warran et al., 2019) and exercise (Casla et al., 2015; Ray & Verhoef, 2013) for women with breast cancer. Other participants found new meaning in simple pleasures such as spending time in nature (Blaschke, 2017) and their

relationships with their pets. Finding meaning in nature is also consistent with the existential coping strategy' spiritual sanctification of nature (Ahmadi, 2006; Ahmadi & Ahmadi, 2015) However, it could also be interpreted as coping by finding meaning in ordinary events described in the meaning-focused coping theory (Folkman & Moskowitz, 2000; Folkman & Moskowitz, 2007). Salander (2018) declares that everyday life and finding meaning in ordinary events are essential ways that people cope with existential distress. He believes that this ought to be the focus of research on coping with existential distress rather than trying to understand existential distress in terms of spirituality. He proposes an alternative theoretical outline of everyday life as a powerful external entity that can provide protection and comfort like the safety and trust created when connecting to religion or nature (Blaschke, 2017; Lilliehorn et al., 2010; Salmon & Young, 2009). The findings in this study section could support and extend the understanding of each of the theoretical views discussed on coping by finding meaning in ordinary events.

Finding meaning in legacy. More than half of the participants discovered a new purpose in life and spoke of the need for legacy. Fay reflected on the notion that having children might be one type of legacy, but one that she did not have, leaving her to think of other ways to cope with understanding the meaning of her life. Beth, Cindy, and Fay felt compelled to support others facing breast cancer in the future, viewing this as a significant legacy and a way to make a difference in the world. This charitable drive is consistent with existential philosophy. Yalom (1980) identified the need for a sense of purpose to cope with the ultimate concerns in life, i.e., isolation, freedom, meaninglessness, and death, all of which can be experienced when diagnosed with cancer. Altruism, dedication to a cause, creativity and self-actualization are ways people can achieve a sense of purpose and believe that their life matters (Yalom, 1980). Unfortunately, specific research on the concept of legacy for women with primary breast cancer is scant. However, the study findings resonate with those of Hunter (2008)who researched the legacy of cancer, focusing on women with advanced cancer using qualitative thematic analysis. Hunter declares, "making meaning of one's life and leaving some sort of mark become much more important to women faced with possible death

after receiving a diagnosis of cancer" (2008 p.119). The findings reported by the participants of my study echo this wish. In addition, they add to the literature by illustrating that the relationship between meaning in life and a sense of purpose and legacy is also essential for women who have survived treatment for primary breast cancer but do not have advanced disease.

iv) Relevance of spirituality to clinical practice. This section of the study extends understanding of the lived experiences related to spirituality for women with primary breast cancer. The findings are relevant for clinical practice because they illustrate the complexities of the spiritual dimension and the centrality of it at the heart of coping with the need to make sense of life when faced with existential distress. In my clinical experience, spiritual concerns can be the most crucial issue clients with cancer want to explore. It is essential to be sensitive to spiritual needs that may or may not be grounded in religion in a multicultural society like the UK. Clinicians need to avoid making assumptions while bracketing or suspending their spiritual values and beliefs while working with others who may hold opposing views. White (2006) maintains that clinicians who are self-aware and comfortable with their spirituality are better able to invite others to examine spiritual concerns. Others argue that clinicians need to be open to the idea that people with cancer can cope with existential questions in terms of attachment to their routine activities of daily living and question the need for referrals to specialist existential therapies to cope with the givens of life (Salander, 2018).

# 5.1.7 The Experience of Time & Temporality

Warnock (1970) offers a concise explanation of Heideggerian ideas on time and temporality. Temporality is the way humans exist in time. We are always aware of the past, "the facticity of ourselves in the world", the present, "the immediate business of the moment", and the future "possibilities for ourselves", noting that the future orientation is the most important (Warnock, 1970, p.62-63). In addition, the sense of self is thought to be underpinned by a temporal continuity of consciousness (Husserl et al., 2019). Temporality is lived through, but according to Straus (1947), not always the object of conscious experience. Minkowski (1970) proposed that time is experienced

as subjective lived time rather than objective, measurable time. Phenomenological psychiatry views temporality as main construct to understand psychopathological deviations of time experience. Fuchs differentiates between implicit and explicit temporality. For example, implicit temporality is lived time when we are in flow, not noticing time as we are absorbed in the task at hand. In contrast, explicit temporality is experienced when time is felt, such as in waiting or in illness, and is explicit because it enters conscious awareness (Fuchs, 2005; Fuchs, 2013) . Like Heidegger (1962), Minkowski (1970) asserts that orienting life towards the future gives life meaning and direction. People can be left to cope with meaninglessness and existential despair when the future is disrupted.

Although there is a vast amount of research on primary breast cancer, most qualitative research has focused on general lived experience, with few studies focusing specifically on time experiences (Martino & Freda, 2016). For example, research on lived time in cancer has focused on palliative care with mixed populations (Dalgaard & Delmar, 2008; Ellingsen et al., 2013), cancer survivors with mixed populations (Rasmussen & Elverdam, 2007), temporal experiences of gastrointestinal cancer (Khatri et al., 2012), lived time in ovarian cancer (Moskalewicz et al., 2022), and the temporal paradox of chemotherapy for women with ovarian cancer (Moskalewicz et al., 2021). The findings of this study illuminate the relationship between experiential lived time and coping with explicit temporality revealed as the participants adjusted to living with breast cancer across all the four worlds of existence.

i) Perception of the Speed of Time. The study participants described how they experienced time differently at varying points during their treatment and how their perceptions of the speed of time depended on the context. For example, at the beginning of the cancer experience, participants reported disrupted time as they tried to process the initial shock and meaning of a breast cancer diagnosis. Conversely, they described a sense of time being stretched and slowed as they waited for confirmation of their cancer diagnosis and needing more time than usual for cognitive processing of this distressing event. Coping literature supports these findings on the relationship between time

and context, acknowledging how coping responses are impacted depending on the time of the stressor (Carver et al., 1993b; Osowiecki & Compas, 1999). In addition, these findings are consistent with the concept of 'changing pace of perceived time' reported in a study on temporal experience with people with gastrointestinal cancer (Khatri et al., 2012).

Later, when participants commenced cancer treatments, time took on different meanings. Post-surgery time took on both slowed and accelerated qualities leaving participants to cope with making sense of these dichotomies by reflecting on their experiences and assigning meaning to them. The chemotherapy participants reported how treatments took over their time as they accommodated the cyclical treatment pattern. They coped by living in the present (Brown, P. & de Graaf, 2013), day by day in a repeating three-weekly cycle that left some feeling stuck and paralyzed in time. For example, Fay explained how she experienced the world continuing without her, comparing herself to others living their lives while she was stuck in a three-week cycle. Being stuck in the present with an uncertain view of future possibilities left the participants to cope with existential distress. This example of disrupted time and increased awareness of time is consistent with studies on cancer survivors (Rasmussen & Elverdam, 2007). In addition, the findings also resonate with a specific time disruption reported in relation to chemotherapy treatment by Moskalewicz et al. (2021) . They described the paradoxes of 'chemo-clock' and 'short temporal horizon' observed in their study on experiences of time for women receiving chemotherapy for ovarian cancer. The findings of my study confirms that women with breast cancer report similar experiences.

The end of cancer treatment was considered a crucial point in both implicit and explicit time for study participants, one marked by anxiety and is consistent with breast cancer literature (Hewitt et al., 2005; Lethborg et al., 2003). All participants reported how their situational context was linked to changes in perception of time, particularly when attending ongoing medical checkups such as annual mammography and routine follow-up appointments to monitor hormone therapies, both of which occur for extended periods of between five and ten years for women who survive breast cancer. The threat of cancer recurrence is real for these women who shared how time took on new

meaning and slowed when waiting for results after scans and blood tests. Anxiety arises when remembering cancer at these critical points, then dissipates until the next time life is interrupted by reminders of past illness.

ii) Meaning of Time Shaped by Mortality. Time took on new meaning for participants as they took stock of their lives. Reflecting on the past raised awareness for the study participants of the limits of life as they noticed how fast their lives had already passed as they contemplated an uncertain future. Participants coped with facing mortality by choosing how to make the best use of the time they had left which is consistent with other studies (Khatri et al., 2012; Martino & Freda, 2016; Rasmussen & Elverdam, 2007). Focusing on the future was a coping strategy that helped most study participants tolerate difficulties they experienced in the present during cancer treatments. By distracting themselves with hope and wishful thinking, participants avoided thinking about illness and the things that were out of their control while holding on to the hope of better days ahead. This finding is consistent with the notion of the importance of a future orientation related to finding meaning in experience (Heidegger, 1962; Minkowski, 1970). In contrast, two participants held less optimistic views for the future and coped by wishing for a return to their past lives before breast cancer while knowing that this was impossible. Studies on the relationship between the experience of time and depression show that depressed people tend to be preoccupied with past events and are less focused on the present or future (Gallagher, 2012). Furthermore, both study participants who were preoccupied with their pasts faced a crisis of meaninglessness that emerged when facing mortality and loss of hope for the future. These findings point to the clinical significance of time orientation when working with women with breast cancer at any stage of the disease.

iii) Timing of Support Services. Participants shared their experiences of timing of and access to support services. There was a preference for psychological support offered at the end of treatment when they felt alone and isolated without regular contact with the medical team rather than in the early stages of the cancer trajectory. Cindy provided an excellent example of attending a support group too early in her cancer journey, resulting in more psychological suffering than relief.

Participants in this study also shed light on the kinds of support they had access to and how these were often time-limited services. In theory, time-limited services are a solution to offer ongoing support to a large group of service users. However, this study identified some gaps in psychological services and complementary therapies that left participants to seek help from private practitioners. Most notably was the perceived shortage of access to necessary aftercare such as lymphatic drainage massage, which raises the economic burden of breast cancer for women with long-term lymphoedema, a chronic condition with both physical and psychological repercussions. Clinicians must consider the risks and benefits of the type of support on offer and the timing of such assistance.

# **5.2 Research to Practice Implications**

The findings of the study highlight implications for practice. This section will discuss clinical implications for psychologists and psychotherapists and the wider field of health care professionals and policy makers. I argue the case for access to ongoing psychosocial support for women with breast cancer particularly existentially informed psychological therapies and complementary therapies. I will also consider social justice and cultural differences in relation to potential health inequalities.

## 5.2.1 Clinical Implications for Psychologists and Psychotherapists

Evidence-based psychological therapies to support cancer patients are well documented in psycho-oncology literature (Watson & Kissane, 2011). Approaches include Cognitive Behavioral Therapy (Horne & Watson, 2011), Supportive Psychotherapy (Lederberg & Holland, 2011), Cognitive Analytic Therapy (Pitceathly et al., 2011), Mindfulness-Based Interventions (Payne, 2011), Narrative Therapy (Snedker Boman, 2011) and both Meaning-Centered Group Psychotherapy and Individual Meaning-Centered Psychotherapy (Breitbart, William & Applebaum, 2011; Breitbart, William S. & Poppito, 2015).

Although meaning-centered therapies address existential themes in individual and group settings, they offer manualized approaches to psychotherapy (Breitbart & Applebaum, 2011; Breitbart & Poppito, 2015). Truijens et al. (2019) reviewed empirical evidence for the assumption that manualized psychological treatment is more effective than non-manualized approaches. Their study points to the ongoing scholarly debate about using manuals in clinical practice. For example, some authors suggest difficulties in tailoring manual-based treatments to the needs of individual clients (Hucker & McCabe, 2012; Marshall, 2009)while others recognize the potential for clinical flexibility (Hamilton et al., 2008). The conclusion is that although manual-based treatments are useful as research tools, they should not be regarded as better than non-manualized psychotherapy for clinical practice (Truijens et al., 2019).

In a recent systematic review and meta-analysis on the effectiveness of psychological treatments in women with breast cancer, Guarino et al. (2020) compared studies on three group interventions: cognitive behavioural therapy (CBT), supportive-expressive therapies (SET), and psychoeducational therapies (PET) focusing on anxiety, depression, mood, and quality of life as outcomes. They concluded that the higher efficacy of CBT might be related to the inclusion of mindfulness-based interventions such as mindfulness-based cognitive therapy (MBCT), and recommend CBT, SET and PET group therapies as the gold standard treatments for women with breast cancer. However, they also point to the need for further studies on other therapeutic approaches, including individual therapies with women at different stages of breast cancer, and echo an observation by Beatty et al. (2018) who suggested that since breast cancer treatment has changed in recent times, so too might approaches to psychological therapy in the context of breast cancer evolve.

A systematic review and meta-analysis of randomized control trials studying the effects of existential interventions on spiritual, psychological, and physical well-being in adults with cancer provide evidence that adults at all stages of cancer, and all types of cancer could benefit from existential interventions (Bauereiß et al., 2018). However, of the twenty-four randomized control

studies included in this review the majority focused on people with advanced cancer. (Breitbart, William et al., 2010; Breitbart et al., 2015; Chochinov et al., 2011; Kissane et al., 2007a). Existential interventions with advanced cancer patients included: short-term life review (Ando, M. et al., 2010) , meaning-centred group psychotherapy (Breitbart et al., 2010; Breitbart et al., 2015), supportiveexpressive group therapy (Butler et al., 2009; Kissane et al., 2007b), dignity therapy (Chochinov et al., 2011), hope interventions (Duggleby et al., 2007; Herth, 2000), meaning-making intervention (Henry et al., 2010), narrative intervention (Lloyd-Williams et al., 2012; Lloyd-Williams et al., 2018), and meaning of life while managing cancer interventions (Lo et al., 2019; Mok et al., 2012) . Only six papers specifically focused on women with early-stage breast cancer. The types of existential interventions with this population included supportive-expressive group therapy (Carlson et al., 2016; Classen et al., 2008; Ho et al., 2016; Tabrizi et al., 2016), cognitive-existential group therapy (Kissane et al., 2003), and meaning-making interventions (Lee et al., 2006). The review was limited in that it focused primarily on group modalities. In addition, as observed by Vos (2015) psychotherapeutic help in the form of meaning making interventions only address meaning in life while supportive-expressive therapy tends to address existential concerns. Vos highlights how the relationship between meaning and existential concerns are relatively unexplored, leaving it difficult for practitioners to integrate them. There is a gap in the literature pointing to the lack of evidence for individual existential phenomenological psychotherapy approaches that could integrate both search for meaning and exploration of existential concerns. This could be helpful for women with primary breast cancer struggling to cope with existential distress.

The findings of this study address the gap in the literature and lend support for the use of an existential approach such as that of the British school of existential analysis, that offers diverse theoretical approaches grounded in existential philosophy, of which Emmy van Deurzen (2010; 2012; 2015), Ernesto Spinelli (2015) and Hans Cohn (1997) are the most influential advocates (Cooper, 2003). Spinelli (2015) offers an approach to individual existential-phenomenological enquiry that values the stances of being-with and being-for clients and is viewed as more phenomenologically

focused compared to van Deurzen who is more philosophically aligned. Despite the different existential approaches, they share common features including a focus on the personal experience of individual clients using a phenomenological method and paying attention to an ontic-ontological analysis of ways of being in the world (Correia et al., 2018).

## 5.2.2 Suggested Use of Four Dimensions Framework for Exploring Coping in Psychotherapy

The four dimensions model is recommended by this writer as a framework that could guide practitioners who are working with women facing life after breast cancer. It has been successfully incorporated into existential time-limited therapy by Strasser and Strasser (1997). Future research is needed to establish evidence for integration with other modalities serving oncology populations.

The number of women facing breast cancer is expected to rise sharply over the next decade (Breast Cancer Now., n.d.). Psychologists and psychotherapists need to be prepared to meet with clients who might present with psychological concerns related to physical health issues. The adapted model of the Four Worlds, based on the work of Emmy van Deurzen (2010) in Figure 1 (see p.167), can guide practitioners and help facilitate an exploration of how clients are coping with the givens of their lives. This exploration could lead to new understanding of beliefs and values, highlighting what is and what is not in the client's control, and facilitate attitudinal changes. Such a search for meaning and the identification of personal coping repertoires can help clients make sense out of their lives and feel more empowered to manage their life dilemmas.

In the physical dimension clients might benefit from describing their embodied experience. What is it like to be in their body and acknowledge the changes between the before and after breast cancer? The client may need to address issues of grief and loss as they adjust to their new experiences of embodiment. Some clients, like women in this study, might find new appreciation for their body, giving them new meaning relating to attunement listening to felt senses and confidence that they can cope. Exploring embodiment might help clients identify how they are managing

symptoms related to cancer treatment. This could lead to new understanding and uncover options for coping with related distress that may not have been immediately obvious to them.

Issues relating to body shame and self-disgust are potential dilemmas that could lead to serious distress for women with breast cancer and be catalysts that bring such clients to therapy. One way to facilitate an exploration for meaning related to a dilemma like shame and self-disgust would be to look at it through each of the four dimensions and in relation to time. For example, the physical dimension could illuminate pain and tenderness in the reconstructed breast or at the surgical site. Each of the following situations could lend itself to exploration using an existential-phenomenological approach to psychotherapy. For example, Emma could spend time reviewing her values to discover what it means to her to be physically overweight and the implications of her physical size on her global lived experience and sense of self. Heather might be reminded of her cancer each time she tends to her swollen arm. Working with the meaning of her lymphoedema could allow for new interpretations and choice in how Heather decides to relate to her changed body.

The personal dimension could explore related thoughts and feelings, for example about pain. This could lead to awareness of meaning that is attached to pain such as facing limits in life, which can also hold implications for facing mortality. How the client portrays herself might reveal her need to cope with an altered sense of self. Exploring how she coped with difficulties in the past might shine light on options available to her in her current situation.

From a social dimension the issue of shame and self-disgust takes on different meaning as women might grapple with that other people might think when they see their body. Sitting with ambiguity in the gaze of others can be difficult. One study participant, Allison, thought she looked like 'Picasso woman' while her husband said she looked fine to him. These incongruent views can be explored, opening the client to the possibility that each person might hold a different viewpoint and interpretation of the facts. This type of curious exploration about how we think other people think allows for broader empathic understanding.

# Time **Spiritual Personal** Integrate cancer Altered sense of self. experiences into Benefit finding and worldview. Review strengthening character. beliefs & values, life Life review, future focus purpose and meaning in Coping repertoire & relation to time & Manage fear of recurrence temporality Social **Physical** Meaning in care, relational loss & attachment style, Cope with physical Seek insider knowledge & repercussions of breast peer support. cancer e.g., ongoing HT Meaning of work & side effects, altered body realigning priorities Tolerate the gaze of other

Figure 1 Coping with Primary Breast Cancer illustrating the complexity of each level of lived experience within the Four Dimensions of Existence. Adapted from van Deurzen model *Living with conflict and trauma* (2010 p.142).

Allison hated the look of her body, fixating on the changed breast, but her husband only saw his beautiful wife and all the qualities that make her who she is. By having Allison imagine what the other might see in her beyond the breast could build self-compassion and foster a kinder and gentler attitude towards the self.

Working with the spiritual dimension can be a way of integrating the cancer experience into worldview. Cancer is often a catalyst for an existential awakening and sharp reminder of limits and mortality. Thinking about the spiritual side of life provides insight into beliefs and values and meaning that transcends physical limits.

Exploring the experience of time and temporality offers women with breast cancer an opportunity to look back on life and focus on hopes for the future. Fear of disease recurrence is a complex issue that can also be related to the relationship with the body. Women might feel that their body let them down once and they may no longer trust their body after breast cancer.

According to Cohn, existential-phenomenological psychotherapy can do two things; "it could enable us to accept the inevitable characteristics of existence - like being in the body, being with others, the necessity of choice, the certainty of death. But it could also help us to affirm the possibility of choosing our own specific responses to what is 'given'" (Cohn, 1997, p.125) . This statement supports the view that coping in existential terms is about active engagement in attitudinal choice.

# **5.2.3** Implications for Medical Professionals

This study confirmed how participants coped in different ways at different times during their cancer journeys. Some reported difficulties in coping with anxiety at the end of breast cancer treatment. Although this is well documented in the literature (Harris, J. et al., 2017; PDQ® Supportive and Palliative Care Editorial Board. & National Cancer Institute, 2021) it is important for medical professionals to recognize that patients can be helped by a variety of emotional and social support services and that they might be relied upon to make timely and appropriate referrals. The

National Cancer Institute in the United States publish online peer reviewed resources for both medical professionals and cancer patients. NCI PDQ cancer information summary about adjustment to cancer anxiety related to breast cancer recommends the following services: relaxation training, psychotherapy or counselling, cancer education sessions, Existential therapy, and social support in a group setting. However, in the UK the NICE Guidelines for the provision of psychological support for people with breast cancer is less specific. NICE suggests the provision of a named clinical nurse specialist to provide continued psychosocial support throughout treatment from diagnosis to follow-up, with a provision for timely access to specialist psychological or psychiatric services as needed. Unlike the NCI, NICE does not specify any theoretical approach to psychotherapy.

Medical professionals need to be cognizant of the potential for iatrogenic trauma during cancer treatments which might contribute to the need for psycho-oncology support services.

Participants in this study spoke of feeling traumatized during radiotherapy having to lie still and manage their breathing, they shared how they disconnected from their sense of self to cope with revealing their naked bodies during treatment and investigations. Participants also reported on the impact of having to cope with surgical iatrogenic trauma, which is consistent with the literature (Marchettini et al., 2001; Voigt et al., 2017). Other research points to elevated risk of post-traumatic stress in women with breast cancer linking the effects of anti-endocrine hormone therapies such as Tamoxifen with increased anxiety and depression (Brown, L. C. et al., 2020; Rocha-Cadman et al., 2012). Another side effect of hormone therapies for clinicians to think about is the wider health implications in the potential meaning of vaginal dryness for women on HT after breast cancer. Not only does vaginal dryness contribute to dyspareunia, the effects of vaginal pain and discomfort could also hold implications that could impact on other preventative women's health matters, such as avoiding future gynaecological check-ups such as cervical PAP smears.

#### 5.2.4 Implications for Social Justice and Cultural Sensitivity

Health inequalities need to be acknowledged so that they can be addressed by health policy makers. This study confirmed how breast cancer can left people to cope with wider health implications, such as managing long-term burdens of breast cancer like lymphoedema. Regular access to lymphatic drainage massage in the UK within the health service is limited, leaving women with economic burdens. These financial costs might prove more difficult for women with fewer socioeconomic advantages, widening the gap in health inequalities (Phelan et al., 2010). Access to mammography for screening and early detection of disease is another area of concern for social inequalities within preventative medicine. Mobile mammography is one solution that has shown some promise in reducing social and geographical health inequalities (Guillaume et al., 2017)

Cultural sensitivity needs to be considered to better understand coping for women with breast cancer across multicultural and faith groups in the UK. The small number of participants in this study all shared similar culture and ethnicity, but the findings related to how participants coped with feeling exposed during medical investigations such as dealing with having to contend with male radiologists, raise important questions for other women in the UK of multicultural ethnicity and faiths. For example, one question arising from this study relates to the sexual objectification of women's bodies in Western culture, specifically what it means for women to expose their breasts. In a multicultural society like the UK, this finding has significant ramifications relating to cultural and religious differences. Healthcare providers and psychologists need to be sensitive to the multicultural needs of women, for example, those of the Islamic faith from the African, South Asian, and Arabic cultural backgrounds who highly value modesty. Procedures such as mammography could potentially leave some Muslim women feeling uncomfortable due to the need to expose their bodies, particularly in front of male practitioners. An American study has shown that a disproportionate burden of breast cancer mortality and low uptake of available mammography

screening persists in minority groups such as Muslim women (Padela et al., 2016). Similar studies could be an area for future research to learn more about minority women in the UK.

## 5.3 Strengths and Limitations of the Study

Although this study has limitations, this does not mean that the findings do not have value. This study has depth and provides transferrable clinical results that could inform therapeutic approaches, particularly the inclusion of existential approaches when working with breast cancer survivors. In addition, it may be helpful and empowering for women newly diagnosed with breast cancer to identify with the narratives of the study participants and foster ways of coping to help them face existential distress.

# 5.3.1 Discussion of Methodology

The existential framework of the four dimensions offers a theoretical understanding of human existence that helps to uncover and facilitate a deeper understanding of subjective meanings of experience (van Deurzen, 2010). The dimensions of life exist jointly like strands of threads spun together, making up the fibre of life. These ideas of interconnectivity are essential when considering the nature of coping with life governed by existential givens and limit situations. Coping is dynamic; there is a ripple effect for each action, ad infinitum. It is clear from the findings that coping strategies and styles overlap across the theoretical life dimensions but organizing the findings in this way highlighted how different concerns required diverse ways of coping. For example, physical concerns such as pain first needed problem-solving coping interventions such as pain management. But once immediate physical needs were met, participants then had time to consider wider implications of pain. Some worried and faced uncertainty, questioning if their pain would be temporary or chronic. Facing uncertainty can lead to existential distress, expressed by worrying how implications of chronic pain might impact upon their wider worldview and future.

In this IPA study the analysis of the interview transcripts required an iterative process, circling back over each transcript to identify initially what the participants had to cope with, and then a second level of interpretation was required to establish how they coped with the challenges described. The analysis of how participants coped required the researcher to adapt a coping language. Having completed a thorough literature review and because of my psychology training I was aware of multiple coping models and theoretical frameworks. I thought it would be important to use words that offered a broad understanding of ways of coping that could be compared to the existing coping literature to position the findings within existing coping knowledge and nomenclature. That said, I was sensitive to the need to remain true to the data, first compiling a list of ways of coping and then interpreting them into coping language, outlining strategies that could meaningfully situate the findings within the existing coping nomenclature.

# 5.3.2 Strengths of Key Findings

This study is important because it extends current cognitive-behavioural theoretical understandings of meaning-making coping, positioning existential coping as intentional engagement with attitudes related to existential givens. Study participants coped by taking action to regain a sense of control over their lives. They trusted others particularly finding meaning in medical relationships which highlighted the paradoxical nature of coping. For example, what first appeared to be ceding control by trusting expert others, could also be interpreted as coping where participants used vicarious control as described by Folkman (1984, p.844). By giving power and responsibility for the outcome of their cancer treatment to the experts, participants were able to reduce the anxiety that often accompany the existential given of responsibility for choice.

Participants in this study engaged in meaning-focused coping by adjusting priorities, realigning values, and benefit finding. Practicing self-care was an important way of coping, as was living in the present while holding on to hope for the future. The study findings also point to the existential nature of important issues reported by the participants, such as death anxiety in the face

of fear of cancer recurrence and questioning the meaning of life while adjusting to an altered sense of self. These findings agree with observations made by Vos (2015, pp.889-890) who expands upon meaning and existential givens in his research with cancer patients. Vos draws on the writing of Heidegger explaining how meaning is revealed in the existential givens. From an existential perspective coping involves facing into, or confronting existential givens, such as death anxiety in serious illness, and tolerating the uncertainty of an existential crisis, in which old meanings can be exchanged for new ones, through a process of cognitive adjustments. This study adds to the knowledge base, enhancing the understanding of coping for women living with primary breast cancer. The findings of this study could be starting points for future more extensive grounded theory studies to formulate a theory of existential coping.

# 5.3.3 Limits of the Study

Due to the nature of IPA qualitative research and the small specific sample size of this study, it is limited in that its findings are not generalizable, nor can they be used to predict or determine causal relationships. The study also is limited by the specific sample of white British women who each hold economic privileges. Their experiences, particularly their options and choices related to work and accessing supportive therapies, illustrate economic advantages and point to the need for further research with a sample of women who may have fewer social advantages.

The ages of participants limit the study because coping with breast cancer for younger women could reveal different concerns and dilemmas that are age related, such as coping with making decisions regarding whether to have children or not, which were not considered in this study.

The sample was also limited because all the participants had a diagnosis of primary breast cancer, with a life expectancy of at least five to ten years and probably much longer. Coping strategies and styles might be different for women with more advanced disease and poorer prognosis, such as coping with the implications of a shorter life expectancy. Further research is

needed that includes women living with metastatic breast cancer, who might have different experiences of coping, to extend the knowledge of what women cope with during all stages of breast cancer.

Finally, the findings could be limited by researcher bias and could be subject to alternative interpretations by other researchers. To limit researcher bias and maintain validity of the study the researcher maintained a reflexive stance to produce a credible, ethically sound study that is sensitive to context, by drawing on existing literature and interview data from consenting participants. The study is rigorous because good quality interviews provided a rich data source for data analysis and the findings have been presented in a transparent and coherent manner.

### 5.4 Reflexivity on the Dilemmas of the Knowledge Journey in the Research Process

A clear consideration of the researchers influence on qualitative research is the process of reflexivity (Yardley, 2015). I recognize that prior learning and life experiences have shaped who I am as a person. They have also influenced my interest in this research topic, which is important to me both personally and professionally. In this section I will outline my research process and immersion in reflexivity to ensure the validity of the study.

i) Acknowledging Personal Insider Knowledge. Although I have not directly experienced breast cancer, I have had breast health issues, and this gives me a unique perspective of insider knowledge. In December 2018, I was recalled after a routine mammogram and experienced time standing still as I waited for follow-up appointments. It was a difficult period waiting over the Christmas holidays, I remember thinking 'this could be my last Christmas' and entangled in my thoughts of dying and leaving my family, there was also thread of rage at the universe, 'how could this be happening now, I have not got time for this, and what about my research and my doctorate?' The idea that I could be thwarted and derailed from my life project almost upset me almost as much as death. This was my second breast cancer scare, having had symptoms that required surgical biopsies twenty years previously. The flood of relief when hearing the words 'it is benign, nothing to

worry about' allowed me to inhale deeply and grasp the myth, once again, that death for me was still a distant future event. Although my personal experience could be viewed as having insider knowledge, I do recognize that it is also different from that of the study participants because I did not have breast cancer.

ii) Acknowledging Prior Professional Knowledge. Witnessing the impact of breast cancer on women and their families and through my work as a registered nurse, then later in the role of art therapist and most recently as a trainee counselling psychologist have given me experiential knowledge. I have experienced the suffering of others, although I did not feel their subjective pain, I have empathized with each as a fellow human, as they coped with breast cancer. These understandings have afforded me with second-person perspective knowledge (Carel, 2016).

iii) Awareness of Assumptions While Remaining Open to Study Findings. All-my life experiences informed my expectations and assumptions of what I thought this research might find. I thought that waiting for results after mammography and breast biopsies would be difficult and frightening. I thought that the participants would think of death, that they would be distressed by the cancer treatments, particularly the loss of breast tissue after surgery and hair after chemotherapy. I thought they might have felt unheard by the medics and that they might have had to act as advocates for themselves. I thought that they would turn to friends and family for comfort and care, and, also to God. I thought that they might find new meaning in life in relation to awareness of mortality and the limits of time. I thought it would be difficult to cope with breast cancer.

I was surprised by the diversity and depth of the narrative accounts shared by the participants. How they had similar experiences, yet each retained a unique voice, particularly about benefit finding, realigning their priorities, and finding new meaning in life. I was surprised by the meaning found in medical relationships, particularly about the paradoxical nature of coping. What first appeared to be ceding control by trusting expert others, turned out to also having an alternative

interpretation of a coping strategy where participants used vicarious control, giving power and responsibility for the outcome to the experts. This in turn reminded me of the inherent power held by others seen as experts. I was also surprised by the positive stances adopted by finding new appreciation in embodied experiences and appreciation for how hardy their bodies were. I was also interested to learn about the difference in meanings different participants held about the distinctions between 'caring for others' and 'being cared for' and how this intersects with the unique context of individuals life experiences and interpersonal attachment styles.

iv) Conducting Phenomenological Interviews. Reflecting on the process of the interviews I was aware of the potential ethical risks of meeting clients both in person and in online meeting spaces such as Zoom. Before each interview I made certain that I had the participants details on hand to contact them in case of technical difficulties to begin the online meeting interviews. I made sure to present myself as professional by wearing clothing that would not cause offense or attract unwanted attention, and I always maintained professional boundaries. I kept in mind the risks of online meetings such as the potential of reduced ability to read body language of participants or detect early signs warning of distress or agitation. To minimize this risk, I reminded participants that they could stop the interview at any time without justification. Had any participant given me concern I would have stopped the interview. None of the participants appeared to be distressed or uneasy by taking part in the study. In fact, most wanted to be informed of the findings and shared how they wanted to participate because they felt it might help other women with breast cancer.

During the interviews I was aware of needing to get the timing and pace setting accurate. I wanted to be sure to have enough time to cover the questions thoroughly. Before each interview I felt excited and anxious, however I was able to engage with the participants, and the questions and answers flowed in a natural conversational way. One challenge I faced was not to go off track and to keep the focus on the questions about coping. I also had to check myself when listening to narratives of medical trauma, being mindful to listen without commenting and colluding to lead the participants. During the interviews I made every effort to engage with the participants as individuals

respecting each participant's unique account of their experience, acknowledging this was a snapshot framed by the researchers' questions. I used the list of open-ended questions as a guide to make sure each interview participant had an opportunity to speak about their experience in each of the four dimensions and their experience of time. I made use of my therapeutic skills that I have mastered over years of training. Using an existential approach was helpful because it values remaining curious and open to whatever arises in a therapeutic setting. I believe that these skills readily transferred and helped me conduct my research interviews. During the interviews, I recall moments when I felt tears welling up in my eyes, as I experienced a somatic empathic response to witnessing the narrative accounts. For example, the words 'they cut my breast off' left me with a sense of shock and horror that resonated with the trauma the participant described. I felt humbled by the generosity and courage of the participants as they freely shared their insider knowledge, providing detailed descriptions of their lived experience.

v) Use of Research Journal to Record Research Process Experiences and Ideas. After each interview I made notes in my research journal for reflection. I was aware of a sense of vicarious trauma. Listening to narratives evoked old memories of other women with breast cancer. I found the process of listening to the recordings and transcribing the text challenging. Being immersed in these stories required me to take my time and pace myself. At times it was difficult for me on an emotional level to sit immersed in the recorded narratives. The transcription process was slow and involved listening to the recordings repeatedly to transcribe the content accurately. I had to let go of my initial ideas that transcribing would be easy and quick. Instead, it was painstakingly slow for me. I had to accept the need to take my time, to be meticulous as I transcribed each interview to give each text my full attention and ensure accuracy and honour the voices of participants.

During transcript analysis, the immersion in words and the images they conveyed at times left me feeling exhausted. I needed to take breaks from the intensity of the process and practice self-care. In one excerpt from my reflexive journal, I wrote, 'What a difference, I have the option to take a break, but the participant lives this day in and day out; is there any respite for her in this?"

vi) Self-Care During the Research Journey. Practicing self-care included writing in my journal but I also interpreted words into drawn images, to make sense of my feelings in response to what I was witnessing in the interview data. This type of response art making is a well-documented practice of art therapists (Allen, 1995; Harter, 2007; Moon, 2003). In addition to drawing, I also soothed myself by expressing my creativity while knitting. Knitting for me was therapeutic as I engaged with complex patterns designed by my favorite knitting guru, Stephen West. I enjoyed the rhythm of knitting, an activity that engaged both sides of my brain simultaneously. I had artistic freedom to make choices and decisions about colour and materials, but I also felt held within the pattern instructions, providing a map to guide me. I had to think and count as I learned new stitches, but I felt safe contained by the structure of the pattern. Looking back on the tandem process of knitting and doing research it occurs to me that knitting provided a safe, reliable, and predictable counterweight to my anxious moments when I wrestled to make sense of the data. At times my confidence waned as I faced the sheer volume of data, and what it could all mean. Stepping back and taking a break from working on the project allowed me space to rest my analytical braincells. I found that after a period of engagement with creativity I could return to the data refreshed, with new ideas about what it might mean and how to manage the sheer volume of data. Engaging in creativity allowed for the formulation of different ways of thinking about the research that seemed to occur outside of my conscious awareness.

vii) Reducing Unintentional Bias. Throughout the study I reflected on my biases about breast cancer with my research supervisor and in personal psychotherapy, which is a mandatory part of counselling psychology training. After careful consideration I concluded that my insider knowledge is important, but it does not have the same depth as the study participants because I did not have breast cancer. However, my second-person perspectives did inform my expectations and assumptions and I acknowledged that they would need to be bracketed. I am also aware that as much as I might try to bracket out my lifeworld, I am human, and my biases will have influenced how I crafted the interview questions, conducted the interviews, and interpreted the texts.

During the analysis of the data, I was highly aware of my bias related to my nursing background particularly in the descriptions of medical procedures. I carry memories that shape my understanding of what it is to face the physical treatments described by the women in this study. There are things that nurses see in the line of duty that cannot be unseen. I cannot erase my memories, but I am aware of them and believe that this reduced unintentional bias. As I engaged with the texts, I kept checking back to ensure that I was reporting what the participants said and not what I imagined. This task was not easy because some of the descriptions had a visceral impact on me, perhaps because I am also a visual person with a vivid imagination. I was also aware of trying to bracket out more recent knowledge gained during my review of the literature of coping theories and peer reviewed breast cancer studies. This was particularly important while trying to make sense of the ways participants reported how they coped because this information was woven within narratives of lived experiences during their breast cancer journeys and needed to be carefully untangled and extracted from the texts. I was cautious because I did not want to unintentionally reduce the data into preconceived categories and risk missing important themes. Yet to make sense of how participants coped I had to adopt some language from existing coping theories respecting that they are validated descriptors that have become part of the wider psychology vernacular. For example, the term cognitive restructuring holds meaning across most psychology disciplines as a process of changing how one thinks about something.

viii) Honouring Participants Voices. In my clinical work in cancer settings as an art therapist and more recently as a trainee counselling psychologist, I have witnessed the narratives of many women as they wrestled with making sense of the broader meanings of their experience of breast cancer from a psychological perspective. I undertook this research wanting to know more about how women with breast cancer cope and what existential concerns they might face. I am grateful to all the voices who inspired this project. I am indebted to the study participants who generously shared their insider knowledge, shining light on how they coped with the multiple challenges of breast cancer, and helping to extend knowledge that could inform clinical practice going forward.

ix) Acknowledging Subjectivity. I interpreted the data through a lens informed by psychological theories and clinical experience. I chose to explore the data and present the findings using an existential framework of the four dimensions and time because I identified a gap in the existential literature about coping and the use of individual existential psychotherapy with this population. I acknowledge that other researchers could produce different interpretations. Although it is vital to recognize the risks of researcher bias, I also believe that this project has been impacted in positive ways by who I am. While I am a postmenopausal, white, middle-class woman, I am highly aware of my power and privilege, and I take my responsibility for the use of this power very seriously. I care about social justice, particularly health inequalities and women's issues. These values are important to me, and I think they are congruent with maintaining an ethical stance in research practice and align well with my professional identity as a future counselling psychologist.

#### 5.5 Conclusions and Future Directions

The purpose of this study was to explore the phenomenon of coping for women with primary breast cancer across all dimensions of lived experience and in relation to time. The findings presented in Chapter 4 provide detailed insights into what participants faced during their cancer journeys and how they coped with their lived experiences. The study is important because it revealed significant implications for the psychological support of women with primary breast cancer and points to individual differences in coping repertoires and resources. This research confirms much of what is already known, substantiating coping as an important construct for understanding how humans are continuously making efforts to solve or minimize distress. However, the findings of this study also add valuable knowledge because they provide evidence of the existential nature of what participants coped with during their experiences of primary breast cancer and how they coped with existential concerns. All participants coped with existential givens such as freedom to choose, uncertainty, interpersonal relationships, and existential anxiety, in relation to time and temporality across the four dimensions of life. Existential givens are regarded as facts that people cannot

change, but existential psychotherapy proposes that people can change their attitudes about the existential givens they face. This study extends current theoretical concepts of coping with illness to consider coping from an existential perspective as the intentional engagement with attitudes related to existential givens.

# 5.5.1 Synopsis of Key Findings

Study participants described how they managed the physical impact of surgery, chemotherapy, radiotherapy, and ongoing hormone therapies in the physical dimension. They faced existential distress as they confronted the limits of their embodiment and an uncertain future in response to altered perceptions of time and disrupted temporality. In addition, they encountered existential themes of choice and responsibility as they weighed surgical options and choices for ongoing prophylactic therapies.

In the personal dimension participants coped with existential anxiety. They faced both short and longer-term psychological repercussions particularly fear of cancer recurrence related to a heightened awareness of mortality. Beliefs about self-esteem and self-concept were challenged as participants experienced an altered sense of self. Participants described flexibility in coping strategies as they adjusted to the impact of global changes. They coped by reviewing their priorities and values, lived in the present moment, trusted others, and practiced self-care.

Existential anxiety, in the form of isolation and meaninglessness impacted the personal world and social dimension of participants lived experiences. They coped by finding new meaning in relationships, particularly the meaning within medical relationships and the meaning derived from being cared for care and caring for others. Experiences of loss also needed to be attended to by participants in the social dimension. The participants coped by taking action to regain a sense of control when they could by trusting others, engaging in benefit finding, living in the present, seeking meaning in their experiences, and holding on to hope for the future.

Coping related to the spiritual dimension illustrated a relationship between secular beliefs and coping with existential concerns such as death anxiety. Of particular interest is the important role complementary therapies play in spiritual support. Most importantly it was discovered how participants in this study relied upon meaning-focused coping strategies to make sense out of life; they realigned priorities, practiced benefit finding, found meaning in ordinary events, and coped by searching for meaning in legacy.

#### 5.5.2 Recommendations for Future Research.

The findings of this study support the need for future research particularly on the relationship between coping and the temporal experience of breast cancer to understand more about experiences of time across all stages of the illness and recovery trajectory. It would be interesting to consider coping for women with metastatic breast cancer because women are living much longer now with advanced disease. More research is needed to understand coping for women with breast cancer across multicultural and faith groups in the UK. Studies that investigate coping with long-term burdens of breast cancer, particularly health inequalities for women with fewer socioeconomic advantages are also important areas for future enquiry. Future research is also recommended to provide evidence for the efficacy of an existential approach to psychotherapy for this population and the potential to integrate an existential-phenomenological approach into other evidence-based theoretical paradigms. Finally, this study points to the need for further research to validate existential coping within the coping literature.

# 5.5.3 Relevance of Contributions to the Field of Counselling Psychology and Psychotherapy

This study is relevant to the field of counselling psychology and psychotherapy because it adds to the knowledge base enhancing the understanding of the lived experience of coping for women with primary breast cancer, particularly how coping intersects with existential givens. The study provides evidence to support continued provision of and access to psycho-oncology services

for women during all stages of their cancer journey. In addition, this research provides evidence to support an existential clinical approach using models such as The Four Dimensions to guide psychotherapeutic work with clients facing existential givens and potential existential distress.

Exploring how clients are coping across each dimension of lived experience and in relation to time, can facilitate attitudinal changes in individuals' beliefs and values alongside a search for meaning that could enable them to make sense of their situation and feel more empowered to cope.

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# Appendix A

#### Informed Consent Sample Document



The Department of Health and Social Sciences Middlesex University Hendon London NW4 4BT



#### **Written Informed Consent**

Title of Study: The Phenomenon of Coping for Women Survivors of Breast Cancer

Academic Year: 2019/2020

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I have understood the details of the research as explained to me by the researcher, and confirm that I have consented to act as a participant.

I have been given contact details for the researcher in the participant information sheet.

I understand that my participation is entirely voluntary, and that should I want to withdraw from the project and request that my data is destroyed I must request this within one week after the recorded interview, without obligation to explain my reasons for doing so. I understand that after this time it will not be possible to withdraw.

I understand that the data collected during the interview will be anonymized and will be stored securely for up to 10 years.

I further understand that the data I provide may be used for analysis and subsequent publication, and provide my consent that this might occur.

| Participant  | Researcher   |    |
|--|--|----|
| Date   | Date:  |    |
| and the Chair of the School of Social University, if required by institution | inspected by the Chair of the Psychology Ethics Panel<br>al Sciences Ethics Committee of Middlesex<br>nal audits about the correctness of procedures.<br>et confidentiality, please tick here if you do not wish | el |
| your data to be included in audits [   | ]  |    |

#### Appendix B

#### Participant information sheet



The Department of Health and Social Sciences Middlesex University Hendon London NW4 4BT



#### Date:

#### The Phenomenon of Coping for Women Survivors of Breast Cancer

#### Invitation to participate

I invite you to consider participating in my research project exploring how women cope with living with breast cancer. I think it is important to learn more about the lived experience of coping and I believe that you, as a woman who has experienced breast cancer and treatment, will have 'expert insider knowledge' that might be important to share with others.

#### What is the purpose of the research?

The aim of my research is to explore the first hand accounts of coping for women who have survived a breast cancer diagnosis and medical treatments. I hope to give participants a voice to share how they coped with cancer across the four existential dimensions of life. This means exploring not only the physical experience, but also the emotional, relational and spiritual aspects of life. By understanding more about how women cope; some answers might be found for the following questions:

- 1. What does it feel like to cope physically, emotionally, with others, with your sense of self and how does this affect your values and worldview?
- 2. How and when does the need to adjust coping styles manifest?
- 3. Is coping considered important on a personal level when faced with a serious medical condition such as a cancer diagnosis?

My hope is that this research will help both women facing breast cancer and the health care professionals who work with them, to understand more about the lived experience of coping with breast cancer and medical treatments.

#### Why have I been chosen?

You have been selected because you might meet the research criteria, which is as follows:

- 1. Female aged between 40 and 60 years
- 2. Primary diagnosis of breast cancer
- 3. Completed medical treatments (surgery, chemotherapy and radiotherapy) more than three months ago but less than two years ago.

# Do I have to take part?

No. It is your choice to take part only if you want to.

#### What will happen to me if I take part?

You will be invited to meet for an interview that will last for approximately 90 minutes. The interview will be recorded so that information can be gathered from your shared knowledge. All information will be kept confidential, and your name and other identifying information will be made anonymous.

At the end of the interview there will be an opportunity for a short debrief. In addition you will be given information about where you can access further support if required.

## What are the possible disadvantages to taking part?

Remembering and sharing your experiences of coping during your cancer treatment might bring up difficult emotions and / or traumatic memories that may cause you some distress or anxiety.

#### What are the possible advantages of taking part?

You might get positive feelings knowing that you could help other women facing breast cancer be better prepared to cope with their illness and also that you could help counselling psychologist and other helping professionals better understand the experience of coping with life during breast cancer treatment. Some participants also find that talking about their experiences can be therapeutic.

#### Consent

You will be asked to sign a form agreeing that you want to participate in this research study and that you have been given information regarding your participation and right to change your mind.

#### Who is organising and funding the research?

Research is organised and funded by Karen Dyer for the purposes of the requirements for the degree of Doctorate in Counselling Psychology.

## What will happen to the data?

Original tape recordings will be deleted upon transcription and anonymization of data. Physical data in paper form will be kept confidential and stored in locked files accessible only by the researcher. Digital computer files will be encrypted and kept on a password-protected computer that is accessed only by the researcher. The data will be analysed for themes giving deeper understanding about how coping is actually experienced by women who have had breast cancer. The findings will be published as a doctoral dissertation for the degree of Doctorate in Counselling Psychology in partnership with the New School for Psychotherapy and Counselling, awarded by Middlesex University.

<u>Who has reviewed the study?</u> All proposals for research using human participants are reviewed and approved by an Ethics Committee before they can proceed. The NSPC Ethics Committee have reviewed and approved this proposal.

#### Concluding section

Thank you for taking the time to consider participating in this research project.

Researcher: Karen Dyer Supervisor: Dr. Chloe Paidoussis-Mitchell

C/O New School of Psychotherapy and Counselling,

61-63 Fortune Green Road, London NW6 1DR, England

#### Participant Recruitment Poster





# RESEARCH PARTICIPANTS NEEDED

An IPA Study focused on:

# Coping with Breast Cancer

- Are you a woman aged between 40 and 60?
- Have you received treatment for breast cancer within the past 2 years?
- Would you consider being interviewed\* for 90 minutes?
   \*Everything shared will be confidential and anonymous

If you answered yes, please contact me to explore participating

#### Full Study Title:

The Phenomenon of Coping for Women with Breast Cancer

# Research Question:

What is the lived experience of coping with breast cancer?

## For more information please contact:

Principle Researcher: Karen Dyer Email: KD569@live.mdx.ac.uk

Research Supervisor: Dr. Chloe Paidoussis -Mitchell Contact: NSPC, 61-63 Fortune Green, London NW6 1DR

Thank you for considering taking part in this research.

Researcher is a candidate for a Doctorate in Counselling Psychology
The New School for Counselling and Psychotherapy course accredited by Middlesex University

#### Appendix D

#### **Debriefing Form**



The Department of Health and Social Sciences Middlesex University Hendon London NW4 4BT



#### **Debriefing Form**

Title of Study: The Phenomenon of Coping for Women Survivors of Breast Cancer

Academic Year: 2019/2020

Principle Investigator Karen Dyer C/O New School of Psychotherapy and Counselling 61-63 Fortune Green Road London NW6 1DR, England Telephone: +44 (0) 7981819901

Telephone: +44 (0) 798181990: Email: <u>KD569@live.mdx.ac.uk</u>

Research Supervisor
Dr. Chloe Paidoussis-Mitchell
C/O New School of Psychotherapy and Counselling
61-63 Fortune Green Road
London NW6 1DR, England

Telephone: +44 (0) 7764993885 Email: <u>chloe\_paidoussis@hotmail.com</u>

Date:

Dear Participant,

Thank you for participating in this study by sharing your experiences of coping with life after breast cancer. Your insight and knowledge is greatly appreciated.

The aim of this research is to learn about how women who have survived a breast cancer diagnosis and medical treatments cope with various aspects of life, such as their physical, emotional, relational and spiritual experiences of coping.

Your participation is valued because the findings of this research might help medical and psychology professionals have a deeper understanding of what it is to cope with breast cancer. The findings may also help other women facing breast cancer feel more hopeful as they embark on their treatment that they too will cope and make sense out of their experience.

I will transcribe the interview recorded today in order to extract the data. The recording will then be transferred onto an encrypted memory stick and the original will be destroyed. Your transcript will be anonymised and all identifying details will be removed to protect your identity. All written data will be kept in a locked file within a secure room and will be accessed only by the researcher. Any identifiable data will be stored separately from your transcript in a locked file. You have the right to withdraw from the study up to one week from today without prejudice or penalty and request that all your data be destroyed. Your data will be kept for 10 years.

Sometimes when talking about difficult experiences it can be unsettling and result in an emotional response. This debrief is an opportunity to speak about your experience of being interviewed today and discuss anything that the process may have brought up for you. In the event that you feel psychologically distressed by participating in this study, please consult the provided list of counselling support services or contact your GP.

This research will be published as a doctoral dissertation for the degree of Doctorate in Counselling Psychology in partnership with the New School for Psychotherapy and Counselling, awarded by Middlesex University. Upon the completion of this research study the findings will be shared with you by email upon request.

I hope that you have enjoyed participating in this research. Please feel free to ask if you should need more information to complete your understanding of the aims of the research and your participation in it.

Thank you once again for participating in this study.

Karen Dyer

# Appendix E

# **List of Support Resources**

List of Support Resources

Maggie's Centre' Maggie's at The Royal Marsden The Royal Marsden London

Tel: 020 3982 3141

www.maggiescentres.org

# **Paul's Cancer Support Centre**

Tel: 020 7924 3924 www.pauls.org.uk

**SELBCT (South East London Breast Cancer Trust)** 

www.selbct.org

**Breast Cancer Haven** 

www.breastcancerhaven.org.uk

**Breast Cancer Now** 

Tel: 0808 800 6000 (Breast care nurses)

www.breastcancernow.org

# Appendix F

# Samples of Interview Data Analysis

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|--|-------------------------------|--|-------------------------------------|--------------------------------|---|---|---|--|--------------------|
| Descriptive comments   | A                             | w .  | U                                   | Q                              | w   | u.  | Ø   | Ξ  | _                  |
| The first former of productioned graphs can be received with the section which are all the section forms and the section which are all the section forms and the section forms are and the section forms and the section forms are |                               | nerrint #1 Allicon Raw Data  | Descriptive                         | Linguistic                     | Contextual (interrretive  | Emergent Themes   | Connections Arross Themes   | Sinerordinate Themas   |                    |
| Shopes the page of the page of the page of the page of toold whether the page of toold page of the page of the page of toold page of the page of t | 10                            | t question w   |                                     |                                | annual distriction of the second  |   |   |  |                    |
| Here this thing wanted it goes getting that the case before sugar of 'wanting this thing goe I could be an amount in goed to develop the sugar of 'wanting the case of wanting the thing wanting the case of wanting me, wanted be suggert to get the cancer of ASAP and that the case of wanting me, wanted be suggert to get the cancer of ASAP and that the case of wanting me, wanted be suggert to get the cancer of ASAP and that the case of wanting me, wanted be suggert to get the cancer of ASAP and that the case of wanting me, wanted be suggert to get the cancer of the wanting me, wanted be suggert to get the cancer of the wanting me, wanted be suggert to get the cancer of the wanting me, wanted be suggert to get the cancer of the wanting me, wanted be suggert to get the cancer of the cancer of the wanting me, wanted be suggert to get the cancer of the | you<br>66 did<br>ma<br>67 act | u had that surgery, you told me about the emotional support that you not need at that time but then after you had the steedomy what was that like physically how did your body cape the ual body itself. |                                     |                                |   |   |   |  |                    |
| ing and lused to applying mind for a control by the control of a control by the control of a control by the control of a c | - 1<br>88<br>188<br>188       | is is interesting because there was a part of me that when I knew this thing s there I lust wanted it gone I could almost  |                                     |                                | Bodily felt sense before surgery of 'wanting this thing gone I could almost imagine It squirming around and getting its tentacles into thin   | Wanting rid of the cancer   | Control coping - proactive  | Control coping - proactive   |                    |
| Table by the control of the contro   | im<br>69 dri:                 | things and I used to   |                                     | getting tentacles into         | Imagined what cancer looked like - squirming and getting tentacles in<br>her  |   |   |  |                    |
| Variety of the continue of the continue of the continue of the cancer   Variety of the cancer  | 70 You                        | o it and I used to say   | talk to it                          | 700                            | Ritual driving to work – turn music up loud and then talk to cancer "yo are not having me" wanted the surgery to get the cancer out ASAP  | Verbally attack tumor- personified it " <u>you</u> are<br>not having me"          | Anger/Conflict/Ambivalence<br>(Personal World emotional<br>responses) | Personal World emotional responses)  |                    |
| undestaining that there was more than one tumor, place dronged from bunder and industry of bunder than the ancest abosened in the career as government of the career and government o | 71 oh                         | d an MRI scan and said uh  |                                     | L                              | Waiting for further tests /scans to confirm initial diagnosis and plan fr<br>treatment – 'it is unstable'   | Coping with unknown quality and quantity of the cancer                            | Ambiguity   | Uncertainty  |                    |
| the another one photon one can be caused in the caused and the caused and the caused and the caused and the caused is possible to be caused by the caused and the caused is possible to be caused by the caused in the caused is possible to be caused the caused in the caused is possible to be caused the caused in | the<br>72 alw                 | re were three distinct lumps they could see umm and bearing mind i'd ays been for my mammograms so this had all happened   |                                     |                                | understanding that there was move than one tumor, plans changed fro<br>lumpectomy to mastectomy <u>Questioning how well can I know my own</u><br><u>book?</u>   |   |   |  |                    |
| aged in the brainer think on the mastercomy-options limited Atter surgery - relief — Choices limited grattude cancer gone think on the think on the control to be a control to be a control to be an attended the cancer of some control to be an attended the cancer of some control to be an attended the cancer of some control to be an attended to the control to the control to be an attended to the control to the  | wit<br>73 the                 | hin the three year period ummm and there was one there another one re—it was showing up all these other ones so it was a   |                                     |                                | Coming to terms with understanding that the cancer appeared in the<br>three years since last screening – it can happen, be growing in your bo<br>but you are not aware of it.   |   | Ambiguity   | Uncertainty  |                    |
| The bound to decide to go for mattercomy rather than lumpectomy.  The bound to decide to go for mattercomy rather than lumpectomy.  The bound to decide to go for mattercomy rather than lumpectomy.  The bound to decide to go for mattercomy rather than lumpectomy.  The bound to decide to go for mattercomy rather than lumpectomy.  The bound to decide to go for mattercomy rather than lumpectomy.  The bound to decide to go for mattercomy rather than lumpectomy.  The bound to decide to go for mattercomy rather than lumpectomy.  The bound to decide to go for the bound to decide the bound to decide to go for the bound to go for the bound to decide to go for the go for the bound to decide to go for the bound to go for the bound to decide to go for the bound to go for the bound to go for the bound to go for the manning of care and for with for carefrom  The bound to go for the manning of care end for which for carefrom  The bound to go for the manning of care end for the go for the bound to go for the manning of care end for the go for th | no<br>74 fuc                  | ds was thank   | no brainer                          | did not have to<br>think on it | Had to have mastectomy - options limited. After surgery – relief – thankful the cancer is gone  | Choices limited gratitude cancer gone   |   |  |                    |
| ounds horrendous horrendous horrendous horrendous between the service of the control of protection options and the nurses have a single - want in the control of protection options and the nurses horse of the control of protection options and the nurse horse of the control of protection options and the nurse has a service of the control of protection options and the nurse has a service of the control of protection options and the nurse has a service of the control of protection options and the nurse has a service of the control of protection options and the nurse has a service of the control of protection options and the nurse has a service of the control of protection options and the nurse has a service of the control of the contro | to<br>75 not                  | save my nipple a small thing but it makes you feel more normal – I having sing and then later having a reconstruction because  |                                     | save my nipple                 | Multiple tumors – 'It was a no brainer' – meaning did not have to thin too hard to decide to go for mastectomy rather than lumpectomy   |   | Existential Anxiety   | Existential Anxiety  |                    |
| The state of the nurses of the nurses of the nurses are and the nurses of the nurses o | han<br>76 skir                | ving looked into that I just thought oh my god it just sounds horrendous<br>n grafts eight hours on the slab no no If they can do  |                                     |                                |   | Reconstruction options  | Deciding on surgery   | Choice and responsibility  |                    |
| that was not geared of opered for immediate insertion of prothetic treast rather than all Reconstruction options bed stefan about self-maps effect the construction of prothetic treast rather than the construction options are self-maps effect about self-maps effect in managementation immediately – helped feet more normal. Need to feel maps importance of feeling and self-confidence augmentation immediately – helped feet more normal. Need to feel maps importance of feeling and self-confidence augmentation immediately – helped feet more normal. Need to feel maps importance of feeling and self-confidence begins on a general world. Leaded bedat servers under the confidence of | 27 ph)                        | mething straight away that's gonna make me feel better about myself<br>ysically yeah go with that so that's what happened the  |                                     |                                | Thankfuj, felt lucky, that nipple was spared this was important to still have a nipple – what is it about a nipple that is linked to being female   |   | Feminine self   | Altered sense of self  |                    |
| The following the nurses are the tucky that che was able to have ripple sparing mastectomy and and gostiler about tooly image and each tucky that che was able to have ripple sparing mastectomy and and gostiler about tooly image and each positive, better about tool to be on general word. Landed to be on general word Landed to make the state which ward assigned posts of the state to be on general word Landed to make the state which ward assigned posts of the state to be on general word Landed to make the state what's notifier a contract of the state to be on general word Landed to staff to manage the statement and for with for care and for with for care from Landed to the care from the describes experience as hormedous. What is it to care?  The statement of the contract of the contract of the care from the care from the contract of the care from the car | 78 up                         | spital experience was interesting, I was put on a ward that was not geared for breast cancer because they did not have a bed   |                                     |                                | Opted for immediate insertion of prosthetic breast rather than reconstruction to feel better about self- image right away   | Reconstruction options  | Deciding on surgery   | Choice and responsibility  |                    |
| Hospital experience — Impact of no bed on brosst career surgery ward— Lake of choice about certain aspects of care   Existential Anniety   | yor<br>79 on                  | a know it's the way it goes so I was on a general surgical ward the nurses the whole were very nice, one or two that weren't.  |                                     |                                | Felt lucky that she was able to have nipple sparing mastectomy and augmentation immediately – helped feel more normal. Need to feel better about self physically.   | Feminine self image importance of feeling<br>normal and positive about body image | Adjusting to changes in sense of self<br>and self confidence          | Self esteem /self concept  |                    |
| god knows what out sugary surgary a control of the  |                               | believable really but you know there we are the caring profession makes think -1 was in for a day- just one day sent home with   |                                     | wardnot geared<br>up           |   |   | Existential Anxiety   | Existential Anxiety  |                    |
| Pregide views of names as carring professionals—what is it to care? Name of some and for with for carefrom which does it look like to be carefully Mant does it provided to care and for with for carefrom medics care, support care? Seet home with definite describes experience as homedoos wonder  | dra<br>81 of i                | ains hanging out of me that I had to empty blood and god knows what out<br>t was horrendous and the district nurses came in to   |                                     |                                | Questioning efficacy and training of staff to manage breast cancer surgery  | Lack of trust in hospital staff   | Ambivalence   | Psychological  |                    |
| Sent home with drains describes experience as horrendous wonder  | ass<br>82 gav                 | e district nurses  |                                     | care, support                  | Negative views of nurses as caring professionals – what is it to care?<br>What does it look like to be cared for? What does it mean to accept<br>care?  | Need for care and /or wish for carefrom medics                                    | Care - meaning of care  | Care - meaning of care   |                    |
| Analysis Connections across Themes Super-ordinate Themes Table 1 Super-ordinate Themes Sorted by SOTS Sorted by SOTS (2) +   |                               | Analysis Connections across Themes   | r-ordinate Themes                   |                                | ns describes experience as ho<br>Sorted by CATS   | Sorted by SOTS (2)  |   |  |                    |

|  | <b>&gt;</b> |  | £ 1                                      |  | A ZA ZA Clear   | Flash-fill  | > 40                      | i⊞ Group ∨ +;≅ ∰ Analysis Tools<br>ii⊟ Ungroup ∨            |   |
|--|-------------|--|--|--|---|---|---------------------------|---|---|
| ** ** ** ** ** ** ** ** ** ** ** ** **   | Get         | E e  | Geography Automatic Anatomy              | Animals Chemistry Cities   | A A Advanced  | Remove Duplicates                                 |                           |   |   |
| is soon this opposite by the control of the control | 00          | >  | ience you've had, do you think its affec | ted your sense of self   |   |   |                           |   |   |
| The state of the reprince poly what disposal minists is shown that the reprince poly what disposal between the state of th | A           | <b>E</b> D   | O .                                      | Q  | ш   | L   | 9                         | I   | - |
| inquery to a grant one glacent cannot be contained to the beautiful cannot be contained about the coperation of the contained of of the conta | ne #        | Transcript Interview #2. Raw Data<br>Absolutely, when you think about this experience you've had, do you think its<br>affershed varue sense of self.   | Descriptive comments                     | Linguistic comments  | Contextual/Interpretive   | Emergent Themes                                   | Connections Across Themes | Superordinate Themes  |   |
| Figure 1 to be or 10 point (10 to be or 10 to be or  | 220         | any week programmers of the season of the se |  |  |   |   |                           |   |   |
| i imported free been lumibled and integrated by the beached humble, imported a distinct of the library of the l | 33          | How are you, how hove you changed or how are you different now?  |  |  |   |   |                           |   |   |
| Hander Marie 2   Hander Marie 3   Hander 3   Hander Marie 3   Hander Marie 3   Hander Marie 3   Hander 3   Hander Marie 3   Hander Marie 3   Hander Marie 3   Hander 3   Hander Marie 3   Hander 3   Hander Marie 3   Hander 3   Ha   | 223         | Oh gosh, humble, really positive inspired I've been humbled and inspired by the beautiful amazing people I've met in my  |  |  | Sense of self changed - more humble after experience and inspired by others   | Inspired by others                                | Benefit finding           | Interpersonal   |   |
| with partner  for go on a going to go on seption the wing in the fact of being wincertain when or how death will per lead on magnita a well look good.  If a good a going to go does gowen dead 1  with a moderation,  if a meer point on a deed to live with the fact of being witering in the moment  with deas in partner  with a solution of magnita by the care of har medical team who cared for her medical team who cared for her partner  for the magnitar of the moment  with a solution of magnitade of inspiration of magnitade of inspiration  being other, cotally inspired me in my work  were madner own work with other contexts in this way to pay patents  for others. It is this a way to pay patents  for others is this a way to pay patents  for others is this a way to pay patents  for others is this a way to pay patents  for others is this a way to pay patents  for others is this a way to pay patents  for others is this a way to pay patents  for others is this a way to pay patents  for others is this a way to pay patents  for others is this a way to pay patents  for others is this a way to pay patents  for others is this a way to pay patents  for others is this a way to pay patents  for others is this a way to pay patents  for others is the partner of partner of partner patents  for others is this a way to pay patents  for others is the partner of partner patents after for own experience of pring more  for others is the partner of partner patents after for own experience of partner patents in work meaning in work  were meaning in work in community in other 7  for others is the partner patents  for others is the partner of partner patents after for own experience wi |             | journey that's patients fellow patient's humor oh its like one of my girlfriends I love her to<br>pieces   |  |  | Humor helps - funny story of friend who gave absurd gift -' nipple tassels for when you are up and running again girl' Loved this quirky humor - helped her to have a laugh at a time when mood needed a lift?  | Humor   | Humor and absurdity       | Psychological repercussions                                 |   |
| decreted about hair doe carecter pattern and earliering case to tract?  If you are giving to be got in style, unite harmony own might as united about hair doe carecter pattern and about hair doe carecter pattern and about the style and got you might as well look good over control of the style and good your might as well look good over control of the style and good over control of the style | 225         | she sent me a package and there was a couple of nipple tassles   |  |  |   | Importance of sex in relationship<br>with partner | Humor and absurdity       | Psychological repercussions                                 |   |
| Content bair die   Stands wurde with an insider fellow   Inside tellow   Ins   | 226         | she said for when you are up and running girl you know I just loved it you know (laughing)<br>I'm like then I met her for lunch she'd had  |  |  |   |   |                           |   |   |
| If it's gorne get you you might as well lit's meaning death - can over think graturuse for humor - repeats' thank graturuse for humor and absurdity of life. Idea of mortality of life, lidea of mortality of life, lidea of mortality of life, lidea of mortality of life. Idea of mortality of life, lidea of mortality of life, lidea of mortality of life, lidea of mortality of life. Idea of mortality of life, lidea of mortality of life, lidea of mortality of life, lidea of mortality of life you are going to go doop down dead; come but down down down down down down down down   | 227         | Non Hodgkings in her 20s an has had heart surgery so you know she knows suffering I said<br>to her I'm a bit worried ahout hair rive   |  | shared worries with an insider fellow  | Insider - her friend has survived cancer and other medical problems, she knows suffering - one to trust?  | Insider knowledge                                 |                           | Seach for meaning - relational world                        |   |
| Meaning in experience of time   Humor and abburdity  | 228         | this that and the other and she said oh for gods sake if youre going to go love you may as well have your roots done if its gomna  |  | It's meaning death - can over think, gratitude for humor - repeats 'thank you' twice | If you are going to die go in style, using humor again to look at the absurdity of life, Idea of mortality - if its gonna get you , if you are going to die you might as well look good.  |   | Humor and absurdity       | Existential givens: Death anxiety use of dark humor to cope |   |
| Need to live with the fact of being uncertain when or how death will   Need to live with the fact of being uncertain when or how death will   Need to live with the fact of being uncertain when or how death will   Need to live with the want me hair done right   Need to do  |             |  |  |  |   | Meaning in experience of time                     | Humor and absurdity       | Existential givens: Death anxiety use of dark humor to cope |   |
| If a magorie to go droop down dead, I want me hair done right between the humor, works so hard, adorable, kindness inspired by the care of her medical team who cared for her shipped by the care of her medical team and her own work with other cancer patients. Inspired to the care should be best I can ever be, humbled with for others is it is a way to pay back for the care she has received? Flebting splrit for others is she has received? Flebting splrit work meaning in work she meaning in work she meaning in work she meaning in work is a patient? Herbing others in community work meaning to work and gave up other work roles in community work meaning in work is a patient? Proposat to share her experience with others? Regacy personnelling work is a patient? Courage to try something new able to take risk- meaning or trying more important than failure to try? Whats the worst that could happen? Putting  |             |  |  |  | Need to live with the fact of being uncertain when or how death will come but do what you can to enjoy life right now   | live in here and now                              | Uncertainty               | Existential givens: Death anxiety use of dark humor to cope |   |
| humor, works so hard, adorable, kindness hand, adorable, kindness may be care of her medical team who cared for her feat cared about team on the read and her own work with other cancer center as holistic therapist team and her own work with other cancer center as holistic therapist legacy giving back humbled by her work with other cancer patients. A humbled by her work with other cancer patients inspired to do her best from the care she had been humbled with from the care patients of the care she had gave up other work roles in community and charge to the sonaring in work and gave up other work roles in community and the patients of the care patients after her own experience of finding meaning in work work meaning full work meaning for it courage to try something new able to take risk meaning of trying more courage to try something new able to take risk meaning of trying more important than failure to try? Whats the worst that could happen? Putting here is the care of the car |             | heart attack at least I want me hair done right (laughing) and I thought yeah that's what you want   |  |  | Wanting to be like her friend who is living in the moment   | Live in present moment day to day                 | Live in the moment        | benefit finding   |   |
| humor, works so hard, adorable, kindness    Integricable windness   Positive traits of medical team who cared for her region   Positive traits of medical team who cared for her region   Positive traits of medical team who cared for her region   Reason for working in cancer center as holistic therapist   Legacy   Legacy giving back   | 232         | SO having that sort of humor<br>Yeah and humor umm yeah I mean my surgeon bless him works so hard and my breast  |  |  |   |   |                           |   |   |
| best Can ever be, humbled with from the cannot seek that the cannot seek | 233         | Care hurse aborable the knowess of nurses<br>the kindness of the medical team, umm they've inspired me working with cancer patients<br>that I am dissemble to he the user.   |  | Inspired by the care of her medical team and her own work with other                 | Positive traits of medical team who cared for her baseon for undefine in career center as holletic themselves   | Felt cared about                                  | Trust the team            | Interpersonal Finding meaning in relational world           |   |
| inspired me in my work in magnitude of inspiration of magnitude of inspiration of magnitude of inspiration of magnitude of inspiration of magnitude of inspiration being a patient?    Podcast to share her experience with others?   Legacy   | 23.5        | best I can eve to patients and I am humbled with them that I can now pass on and I bear to he is them.   | hact I can awar he humbled with          |  | Humbled by her work with other cancer patients, inspired to do her best for others is this a war to now here for the care she has received?   | Legacy  | hanafit finding           | hanafit finding   |   |
| Not be printed the product of magnitude of inspiration   Now meaning in work meaning to magnitude of inspiration   Description of      | 336         | not that is more than in my work that's which cancer patients but they have inspired me in my work that's which that in my work that in the man in my work that it is not that |  |  | Finds meaning in work as holistic therapist with cancer patients - choice to and do this now and assue on other work roles in community.  | Helping others                                    | Now of princes won        | Interpersonal   |   |
| started a podcast really going for it Podcast to share her experience with others? Legacy benefit finding Courage to try something new able to take risk. meaning of trying more important than failure to try? Whats the worst that could happen? Putting   | 237         | many services and the spend my time helping other cancer patients so totally inspired and this is how I want to spend my time helping other cancer patients so totally inspired me.  |  | Description of magnitude of inspiration  |   | Finding meaning in work                           | work meaningful           | Interpersonal   |   |
| started a podcast really going for it Podcast to state the vesseller going for it Courage to try something new able to that risk, meaning of trying more important than failure to try? Whats the worst that could happen? Putting   | 238         | Really a big shift:  |  |  |   | Legacy  |                           |   |   |
| internal dialogue discussion about   | S           | on ann ive states a potouss so you may it aim really going for it so t thought with not. we spend all our life going oh I cant do, that oh I couldn't do that, and now I'm like hey why not? Whats the worst that can happen?  | Statted a poucast                        | internal dialogue discussion about   | rouces, to state the experience with outers recovered to thy something new able to take risk - meaning of trying more important than failure to try? Whats the worst that could happen? Putting things into new perspective after cancer this is less of a percleved threat |   | Supur Market              | 30 mm m m m m m m m m m m m m m m m m m                     |   |