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Portfolio submitted in fulfillment of the requirements for the

Professional Doctorate in Counselling Psychology

'A Holistic Approach to Care for Women Struggling after

Mastectomy:

An Interpretative Phenomenological Analysis'

Running head: Identity change, self-image and sexual intimacy

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II. Acknowledgements

very foundation of this research and your stories will undoubtedly add valuable information to the field of counselling psychology.

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III. Declaration of Power

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IV. Preface to the Portfolio

Three distinct parts compose my portfolio: A) a qualitative doctoral thesis; B) a publishable paper based on the present study; and C) a combined case study and process report. The most substantial part of this work is the thesis, which is a qualitative exploration of how women experience their femininity and sexuality after mastectomy. The publishable paper is a brief résumé of my participants' experiences across all three themes found. The case study and process report explore the integration of a range of counselling psychology skills used to help a young male client diagnosed with borderline personality disorder who experienced relational difficulties across all his life domains. There are a number of differences between the thesis participants and the client mentioned in the process report/case study and these are age, gender and presentation. Despite the explicit distinction between these two pieces of work, the common theme overarching my work and linking all three pieces is '*the experience of vulnerability'.* Thus, all pieces highlight how individuals make sense of their respective experiences. The theme of vulnerability is tightly connected with my personal and professional journey into becoming a fully qualified counselling psychologist. In order to grant my work as GDPR compliant, I was requested to redact the case study/process report from the final version of my portfolio.

My journey began in my late 20s, with my decision to change careers from working in public relations (PR) to becoming a student counselling psychologist. This decision was an intrinsic part of a lengthy process of self-exploration. I arrived in England alone at the age of 20 and struggled a lot in the first year, having positioned myself in such a vulnerable place. However, facing this vulnerability helped me not only in overcoming social anxiety and depression but also in becoming more open to new opportunities. This experience made me increasingly intrigued about the complexities of navigating a multicultural society and how people from different walks of life relate to each other. When I decided to take more control of my life's path, it was important I did so meaningfully and thoroughly. That was when I decided to take the challenge of shifting from my familiar career position towards the uncertainties that often accompany change.

Studying counselling psychology at undergraduate level as a mature student and working my way up step-by-step was important in helping me develop a new professional identity. Through my higher education, I grew personally and professionally, and my broad academic interests reflect my general openness and curiosity. However, in recent years I noticed my increased interest in women's issues and feminist research – something I can trace back to my childhood and growing up in a male-dominated culture. During my training, including in

the course of this project, I have been refining my skills as a woman counselling psychologist, whilst working with a wide range of vulnerable clients from various cultural backgrounds who are seeking insight and meaningful change. Having learned many approaches to treatment and explored embodiment, I have grown more secure in my practice by making my body available to experience my clients'/participants' world – within the boundaries of professional practice.

Interestingly and perhaps not surprisingly, as I was writing this portfolio I became in touch with my own vulnerable feelings of stress, which had a direct impact on my own physical health. It is worth noting that due to the long hours sitting in front of the computer, I developed severe muscle pain in my neck and shoulders. The headaches were so frequent and intense that after a month I could no longer ignore my body's messages to stop. I suddenly became aware that I was trapped in my mind – overly focused on logic, analysis and results – while disconnected from my body's internal focus and sensations. I then realised that embracing my vulnerability was an important step in surrendering to self-care and the care of others. My approach to treatment was holistic, requiring several osteopathic sessions, massage therapy, Reiki, as well as taking some time off – just what I did not want at that point. However, I was seen and heard, and I was able to re-connect with myself and with those there to help me. Similarly, to my participants and clients, I saw a change in my health status, quickly moving from a fully functioning student position to the uncertainty of depending upon a network of support to recover my wellness. I noticed that this disruption to my daily activities went beyond the fragile condition of my body. I realised that was not just a one-dimensional external physical condition but rather that I had to adapt to a new way of being, which overpowered my choice of work pace. My physical pains expressed a much deeper struggle with stress, and pressure to achieve outcomes expected of me and from me. My own vulnerability needed to be embraced and embodied (physically, emotionally and spiritually) as imperfect, and as asymmetrical as it made me look.

Section A: Doctoral Thesis

'A Holistic Approach to Care for Women Struggling after Mastectomy:

An Interpretative Phenomenological Analysis'

"If you think the value of a woman is only in the curve of her hips and the shape of her breasts, you do not understand how to read beneath her jagged lines, the sacred geometry that make up her glorious heart and her beautiful mind." Nikita Gill

An interpretative phenomenological analysis was used to explore in depth eight women's experiences of femininity and sexuality after mastectomy. My curiosity about these women's issues was as multi-layered as their experiences. In the context of their femininity and sexuality, I was also interested in how body image and self-concept were processed through the embodiment of breast cancer, which in the present cases caused physical transformations and had psychological consequences to wellbeing.

Section B: Publishable Paper

'A Holistic Approach to Care for Women Struggling after Mastectomy:

An Interpretative Phenomenological Analysis'

While considering whether to present one rather than all three themes found in my study, I wrestled with the idea that although it would be beneficial to explore one theme thoroughly, it would feel to me a fragmented way of expressing my participants' stories. The reason why presenting only one theme did not sit well with me was that I don't see them as separate or independent from one another. Rather, they reflect different stages of the same experience, telling a story across time, and as such deserve equal attention. I believe that all themes have practical implications for research on the topic, but, more importantly, they give voice to my participants.

The *Psycho-Oncology Journal* promotes the integration between psychological and oncological issues and it publishes research on the topic. Counselling psychology has much to offer the largely clinically dominated field of oncology. This article argues for a greater psychological input in the treatment of breast cancer by promoting psychological care in the assessment and treatment of emotional issues in oncology patients.

Concluding Comments

In summary, the aim of this portfolio is to evidence the breadth and depth of my research and clinical skills developed throughout the course of my doctoral training. I intend to explore the topic through the relationship between physical and psychological health and how women experience themselves after illness.

Section A: Doctoral Research Paper ⌊SEP⌋

'A Holistic Approach to Care for Women Struggling after Mastectomy:

An Interpretative Phenomenological Analysis'

ABSTRACT

Background: Breast cancer is the most prevalent type of cancer among women worldwide today. Although the number of diagnosed cases continues to increase, the efficacy of treatment has also been improving, allowing survival rates to rise. Breast cancer treatment and surgery often involve a variety of changes in women's appearance, altered sense of identity and relational challenges. A limited amount of research has been found in connection to the subjective embodied experience of women after mastectomy and during rehabilitation.

Purpose: The aim of the present study was to conduct an idiographic exploration of the participants' perceptions of physical and psychological struggles after mastectomy relating to identity change, self-image and sexual intimacy and how these were embodied in the context of overall wellbeing after illness.

Method: This research sought to explore in depth participants' subjective experiences of femininity and sexuality after mastectomy using Interpretative Phenomenological Analysis (IPA) through semi-structured individual interviews.

Results: Three major themes emerged from the data: (1) the '*Ill Self*', (2) the '*Vulnerable Self*' and (3) the '*Coping Self*'. Nine sub-themes emerged from the data: *(1) 'shock', 'pain', 'body-changes', (2) 'control', 'uncertainty', 'other's gaze', (3) 'warrior', 'comparing losses' and 'recovering'.* The themes illustrate a linear but complex experience of women losing their healthy status and functioning to becoming breast cancer patients, and through to recovery. The first major theme – '*Ill Self*' – includes participants' responses to physical and psychological experiences in the context of illness. Participants expressed the difficulties faced in this first stage of diagnosis and how that seemed to have shifted their position from being healthy to becoming a patient. This major theme reflects participants' views on interactions with their bodies and how these are expressed through self-image as they lose/gain body parts (mastectomy and/or reconstruction). The second major theme – *'Vulnerable Self'* – was identified through participants' exposed vulnerability in relational

dynamics but also vulnerability to the challenges presented by illness. Participants revealed conflicts with others and themselves in surrendering and taking power. The *'Vulnerable Self'* also illustrates women's concerns about the *uncertainties* regarding the recovery process and their feelings of exposure to the *other's gaze* during rehabilitation. The third major theme - *'Coping Self'* – is the final identity recognised in the data. I identified the participants' need to gather their remaining emotional resources following a phase of high vulnerability and to continue their journey into recovery and the reestablishment of wellbeing.

My findings explicitly show the need to create a strong professional network of support between counselling psychologists and other relevant healthcare professionals. This network of support relies on the close involvement of clients during assessment and formulation. Designing a holistic treatment plan which is based on individual client needs (identity, relationships, sexual recovery, body image, etc.) but which also accounts for the physical and psychological needs of service users is paramount for the recovery of quality of life after breast cancer.

Conclusion: The findings of this study add to the body of research regarding women's struggles after mastectomy and the embodiment of illness. Participants reported their perceptions and reactions regarding identity change, self-image and sexual intimacy after mastectomy. The participants' desire for a holistic approach to care from specialised services during treatment and recovery was noted. A shortcoming in terms of the provision of psychotherapeutic services to facilitate sensitive communication and follow up on the recovery of breast cancer patients was identified within medical teams, at times of extreme physical and psychological struggle for participants.

Key words: interpretative phenomenological analysis, breast cancer patient's experiences, mastectomy, identity change, self-image, sexual intimacy, embodiment, recovery, holistic care, sensitive communication and counselling psychology.

1. CHAPTER ONE. INTRODUCTION

"One of the most important – and unimportant things – that happens to women when becoming a breast cancer patient is that we are forced to cope not only with the many physical and emotional issues, but also with a major crisis in our femininity, body image and self-esteem."

Jovi Riegler, breast cancer survivor

Overview of the Chapter

In this first chapter, I introduce the topic by providing some background information on the consequences of breast cancer for a woman's sense of femininity and sexuality. Following a brief introduction, I present an overview of the current status of research on the topic and the implications of the present research for the field of counselling psychology. That exploration then leads on to the purpose of this study, highlighting psychological concerns in negotiating sexuality and femininity during breast cancer rehabilitation. I focus on women's experiences of illness while within that exploring how women perceive their bodies, femininity, relationships and sexuality.

1. Introduction

Worldwide, breast cancer is the most common type of cancer found in women, with around 1.7 million cases diagnosed in 2012 (World Cancer Research Fund International, 2018). The latest figures on invasive breast cancer were recorded back in 2015, when 55,122 new cases were found in the UK. Cancer Research UK's latest findings, dating from 2010/2011, show that survival rates are 78% for 10 or more years (females only) and that 27% of cases of breast cancer are preventable (Cancer Research UK, 2018). As the number of diagnosed cases continues to rise, the efficacy of treatment also follows that trend, continuing to increase and allowing survival rates to improve consistently (Matthews, Grunfeld & Turner, 2017). The consequence of that rise is that women with breast cancer are often found in the difficult position of enduring extensive treatment processes (Siegel, Naishadham & Jemal, 2013).

Breast cancer effects, treatment and outcomes vary widely amongst patients, but within the main treatments applied are mastectomy (breast removal surgery), radiotherapy, chemotherapy, hormone therapy and biological therapy. Breast cancer treatments are

applied either individually or combined depending on individual diagnosis and at which stage the cancer was detected. In either case, the course of treatment is discussed within a multidisciplinary team (MDT) in agreement with patients (NHS, 2018). In the UK today, clinicians have a series of NICE Pathways (e.g. advanced breast cancer, early and locally advanced breast cancer) available within the NICE Guidelines (e.g. advanced breast cancer: diagnosis and treatment, early and locally advanced breast cancer: diagnosis and treatment) and for each type of breast cancer diagnosis an equivalent treatment is chosen according to individual needs (NICE, 2018).

When faced with breast cancer diagnosis and its multiple available treatment and surgery options, patients are faced with the difficult decision about whether to have mastectomy or not. The Cancer Research UK presents information about mastectomy versus lumpectomy to help patients gain valuable information about each course of action, and its potential benefits and disadvantages as a way of aiding patients in making an informed decision (Cancer Research UK, 2018). Although lumpectomy and mastectomy are considered equally effective surgical methods, some women opt for removing the entire breast (mastectomy) as they hold the believe that would prevent cancer from returning. Other women may decide to preserve the breast as much as possible and instead opt for having a lumpectomy followed by radiotherapy and in some cases breast reconstruction. Amongst some of the common concerns taken into considerations are feelings about removing breasts (partially or completely, length of treatment to be endured, breast reconstruction (when available) and recovery time after each intervention (Cancer Research UK, 2018). Among some of the psychological benefits associated with breast reconstruction are improvement in body-image and self-esteem through enhanced appearance (Matthews et al., 2017).

The issues (physical and psychological) linked to such treatment have been explored by a variety of researchers both from qualitative and quantitative perspectives. Below, the reader can find some background on some of the consequences of breast cancer with regard to women's sense of femininity and sexuality as well as information on the current status of research on this pertinent topic.

2. Background

2.1. *Consequences of breast cancer for femininity and sexuality*

Although the treatment for breast cancer varies widely according to individual cases, by and large it involves one or more of the following: chemotherapy, radiotherapy, hormone treatment, oral medication and surgery (lumpectomy, mastectomy, breast reconstruction) (White & Hood, 2014). In several cases, treatment and surgery have long-lasting consequences for women's bodies and psyches (Tierney, 2008). A number of studies explored the physical consequences/symptoms of treatment, with findings pointing at unwanted changes in vaginal lubrication (Knobf, 2002), scarring (Boquiren, Esplen, Wong, Toner, Warner, & Malik, 2016), painful intercourse, and lower libido and orgasmic dysfunction (Hungr, Sanchez-Varela & Bober, 2017). Those findings have been reported as seriously troublesome for women's sexual functioning (Safarinejad, Shafiei & Safarinejad, 2013; Boquiren et al., 2016). The psychological consequences of breast cancer treatment have also been found to be significant, with female patients reporting experiences of poorer sense of body image (Donovan, Taliaferro, Alvarez, Jacobsen, Roetzheim, & Wenheim, 2007), feeling less sexually attractive (Beckjord & Compas, 2007), mood disturbance (Matthews et al., 2017), psychosocial morbidity (Matthews et al., 2017) and lower relationships satisfaction (Ganz, Desmond, Belin, Meyerowitz & Rowland, 1999). In the case of mastectomised patients, results from a qualitative study showed changes in women's perception of their femininity. Patients reported feeling less attractive and robbed of their feminine identity after mastectomy (Arroyo & Lopez, 2011). The concept of femininity in this case was closely linked to the loss of breast and therefore loss of womanhood (Arroyo & Lopez, 2011).

Parton, Ussher and Perz (2015) argue that treatment consequences are the product of several changes experienced by women with regard to physical appearance and subjective embodied experiences, not only in treatment but also during rehabilitation. Finlay and Langdridge (2012) state that, *"embodiment is the process or state of living in a body"*. According to Glenberg (2010), psychological processes are intertwined with physicality, motor and sensory systems, and emotions. Thus, sustaining that embodiment is a conscious manner of being, the human bodily context – the body being the vehicle/container through which we experience the world inside and outside of us. That is the context through which we relate to others and process our own inner experiences – feelings, thoughts, and behaviours. Its nature is a subjective felt-sense of the body from inside out with regard to

intention, attention, posture, movement and other processes. The embodiment of experiences is said to contain several layers, through which the world is perceived, and these are the cultural, personal historical, relational and situational context (Glenberg, 2010).

Breast cancer can be perceived as a persistent loss of functioning, given the length of treatment and/or the long-term symptoms (Raggio, Butryn, Arigo, Mikorski & Palmer, 2014). The trauma of being diagnosed and treated for breast cancer poses negative effects on psychosexual functioning in women who present with issues related to poor sense of self-worth as a consequence (Henson, 2002). In many cases, psychosexual concerns are experienced in interpersonal relationships due to the long-lasting effects of treatment such as vaginal dryness and lower libido, to cite a few. Such effects can last well after treatment ends, causing relational difficulties with sexual partners and lowering patients' quality of life (Boquiren et al., 2016). *"Sexuality encompasses feelings about one's own body, the need for touch, interest in sexual activities, communication of one's needs to a partner, and the ability to engage in satisfying sexual activities"* (Wilmoth, 1998). According to Henson (2002), however, women's embodiment of sexuality goes beyond intercourse and it surrounds concepts relating to body image, femininity, motherhood and feeling sexually desired. It also involves more sophisticated mechanisms concerning cognition, psychology and sociocultural domains (Henson, 2002).

2.2. Current status of research in the topic

Quality of life in surviving breast cancer patients is of interest to the field of counselling psychology. Findings from previous studies suggest that cancer patients have the need to gain comprehensible information about diagnosis (Kvale & Bondevik, 2008) and explicit knowledge about potential side effects (Grunfeld, Drudge-Coates, Rixon, Eaton, & Cooper, 2013). Issues connected to changes in femininity (Arroyo & Lopez, 2011), sexuality (Beckjord & Compas, 2007), low self-esteem and relationship difficulties (Ashing-Giwa et al., 2004) are among the difficulties identified in breast cancer patients.

The current knowledge available on the topic, though very valuable, seems overly generalised as it largely measures objectively women's overall sex satisfaction with regards to penetrative frequency (Andersen, 2009). An example of standardised questionnaires is the Appearance Schemas Inventory-Revised (ASI-R), used to gain quantitative results with regard to patient's overall appearance satisfaction after cancers that alter physical image

(Chua, DeSantis, Teo, Fingeret, 2014). Although the results of quantitative studies using objective tools provide useful standardised results based on larger data samples, they leave a gap in terms of the experience of individual differences (Schover, 1991; Slatman, 2014). Quantitative research in the medical field (oncology and gynecology) tends to treat patients in a fragmented fashion, by concentrating mostly on the organic aspects of cancer and failing to sufficiently stress the embodiment of the illness.

3. Implications for Counselling Psychology Research

*"Counselling psychology defines itself as being concerned with the individual's subjective experience, appreciating the complexity of difference and focusing on wellbeing rather than cure" (*Rafalin, 2010, p. 41*).* Honoring its humanistic origins, counselling psychology seeks to understand the meaning clients attribute to personal experiences rather than seeking an established global truth (Rafalin, 2010). The commitment to empirical research is an important aspect of counselling psychologists' identity and a means to seek knowledge about individual cases. However, counselling psychologists view the traditional quantitative methods as incongruent with the idiographic and subjective exploration of client experiences; consequently, a shift into qualitative research has become increasingly popular in the field. Within that shift, the relationship between participant and researcher is at the core of the research enquiry (Rafalin, 2010).

A recently published qualitative study by Larkin, Loaring and Shaw (2015) performed an IPA and found that following mastectomy and breast reconstruction, patients expressed concerns of a psychological nature regarding the renegotiation of sexual intimacy in the context of committed relationships during the recovery phase. As discussed earlier in this chapter, sexuality is an evolving lived experience closely interlaced with the way in which individuals perceive their bodies and themselves (Lehmiller, 2014). While considering the implications of this topic for counselling psychology research, I encountered evidence that healthcare professionals often fail to address sexuality in female patients experiencing breast cancer (Hordern, 2000). Lack of knowledge, personal embarrassment, lack of experience, and not feeling responsible for discussing such information were amongst the reasons found for the poor communication between patient and doctor (Stead, Brown, Fallowfield, & Selby 2003). Hordern (2000) also found that the lack of communication may be due to other factors, including a cultural perspective holding the belief that older women with breast cancer are not in the slightest bit focused on sexuality, instead holding the

assumption that survivorship is the only important aspect of breast cancer and everything else is secondary (Hordern, 2000). This attitude has been identified as an obstacle for clinicians to foster an open exploration of the meaning of intimacy and sexuality in this population. Hordern (2000) proposes that healthcare professionals should discuss the above-mentioned issues with patients irrespective of age, marital status or other factors. The limitations cited above seem to have given rise to a difficulty in addressing important issues regarding femininity and sexuality with breast cancer patients, therefore neglecting important domains of women's wellbeing.

4. Rationale and Aims for Present Research

During my review of the past literature on the topic, I found a common overarching theme: women cancer patients felt apprehensive talking about sexual issues with medical staff, and this lack of rapport added to the existing stress relating to the onset of cancer (Anllo, 2000; Fobair & Spiegel, 2009; Stead et al., 2003). Thus, Attai, Cowher, Al-Hamadani, Schoger, Staley and Landercasper (2015) found that one of the critical areas in need of improvement regarding breast cancer treatment was communication, alongside education, support and shared decision-making. Also noted in the reviewed studies was the compelling evidence that breast cancer can have a significant impact on woman's wellbeing with regard to self-esteem relating to body changes (Parton et al., 2015), self-image (Marshall & Kiemle, 2005), faith (Fatone, Moadel, Foley, Fleming, & Jandorf, 2007), intimacy (Schover, 1991), and sexuality (Schover, Fife, & Gershenson, 1989), both physically and psychologically.

There seems to be a gap in relation to attending to psychological as well as physiological needs of patients in MDT's during breast cancer treatment. Finlay and Langdridge (2012) propose that although embodiment is the link between the human mind and the physical body, in western cultures, the body has traditionally been treated as a biological and material object separated from the mind, holding psychological processes. A limited number of studies exploring the psychological perspective of this topic were found, in comparison with the vast majority stemming from a medical standpoint – oncology or gynaecology (Krychman & Millheiser, 2013), suggesting a split in psychological and medical disciplines. Through research on the unmet needs of breast cancer patients, Soothill, Morris, Harman, Francis, Thomas and McIllmurray (2001) recognised the need to gather and join knowledge from the experiences of various healthcare professionals (nurses, oncologists, psychotherapists, social workers, etc) in providing a comprehensive approach to assessment and treatment.

Soothill et al. (2001) argue for the importance of incorporating psychosocial domains in the overall care plan as a way of reducing cancer-related psychological issues in breast cancer patients. Ghane and Sweeny (2013) approach the topic from a health psychology perspective, which holds a holistic view of the self, proposing that health is composed by three domains: biological, psychological and environmental. A criticism of health psychology states that research tends to focus more on the psychosocial domain, often neglecting the physical domain. In contrast, medical studies often tend to overlook the psychosocial aspects of health in research (Ghane & Sweeny, 2013). Ghane and Sweeny (2013) propose a solution, suggesting that research in health, from both perspectives, should instead take a more holistic approach. That would take the form of incorporating the link between physical and psychological aspects of the self in both disciplines (psychology and medicine).

Due to the current increase in breast cancer in the UK (Cancer Research UK, 2011), concerns regaining sexual health and managing identity as a way of supporting clients in leading a healthy relational life seem to be an issue worthy of further research. The present research intends to add a qualitative contribution to the existing body of knowledge by providing a relevant and rich account of women's perceptions of physical and psychological struggles after mastectomy. Developing a broader understanding of women's subjective, embodied experiences of identity change after illness, self-image and sexual intimacy after mastectomy is an area of great concern in helping survivors make sense of such experiences and improving their quality of life (Reich, Lesur, & Perdrizet-Chevallier, 2008).

The following chapter will provide a critical discussion and overview of the existing literature and methods that have previously been used to measure and explore the topic. The third section will outline and discuss the qualitative methodology chosen (IPA), the participants recruited, my epistemological and ontological positioning, a description of the data-gathering process, the analysis process, a methodological reflection and, finally, the ethical considerations for the proposed research. In the fourth chapter I will present my findings, and a final chapter will discuss the results of my research using the existing research on the topic.

2. CHAPTER TWO. LITERATURE REVIEW

"[…] I think this is such a major change to people's lives, that I think understanding the, you know, where you are going, is so useful, that I thought it would be very useful research. […] I've supported, I've seen patients have mastectomies, and, you know, having great difficulty coming to terms with their life afterwards. Partly because of the big C diagnosis, but partly because of the changes in their body, erm and I just thought it was quite interesting research."

(Fiona, 427)

Overview of the Chapter

In this second chapter, after presenting my aims for my literature review, I break down the chapter into two parts. Firstly, I offer a review of the literature on the concepts of illness, wellness and quality of life (QOL). Nested within this first section, the readers can find psychological views on the process of illness and psychological views on the process of wellness and quality of life. In the second part of this chapter, while reviewing the literature on cancer, identity change, self-image and sexual intimacy, I break the content down into two subsections: the importance of a holistic/psychological perspective on cancer in women, and the psychological perspectives on women's identity, self-image and sexual intimacy within breast cancer. In the first subsection I present the quantitative research on cancer treatment with regard to physiological and psychological changes and consider the importance of taking a holistic approach to cancer treatment issues. Following that, I bring in the qualitative studies on the psychosocial issues of the experience of cancer alongside the limitations found in communication with cancer patients.

Within this second section of the second part, I discuss the psychological perspectives regarding women's identity, self-image and sexual intimacy subsequent to breast cancer. In order to give some context, I break down this second subsection into eight sub-sections: women's sexuality, body image, and intimacy issues across all ages; mastectomy and reconstruction; changed sexuality and body identity; relational changes; ethnic minorities, psychosexual adjustment and psychological interventions; and communication between doctors and patients. The limitations and gaps in existing research are addressed throughout the literature review.

After presenting and discussing all the literature I present a brief summary of the chapter and end with my research question.

1. Aims of the Literature Review

Drawing on Smith, Flowers and Larkin's (2009) suggestions for interpretative phenomenological research, my review of the existing literature functions as a means to gain a better understanding of the chosen topic. My review is based on the existing knowledge around cancer, and an exploration of the areas of women's struggles after breast cancer followed by mastectomy. This literature review aims to critically evaluate the existing research literature relating to cancer in general, and breast cancer specifically, with regard to the holistic (psychological and physical) approach to wellbeing and quality of life. Particular attention is focused on women's embodiment of illness, identity change, self-image and sexual intimacy. I examine research from broad demographic criteria involving a range of ages, educational level, income level, sexual orientation, marital status, types of cancer, and ethnic backgrounds. I focus purely on female participants, as this is the subject of my own study. Through the review, I identify gaps in past research, which I hope to address in the present study.

2. Reviewing the Literature on the Concepts of Illness/Wellness and Quality of Life (QOL)

2.1. Psychological views on the process of illness

Marshall, Lengyel and Menec (2014, p. 198) maintain that *"our bodies are intimately connected to our experience as human beings"*. Through physicality individuals experience a spectrum of sensations from pain to pleasure and manifest illnesses explicitly illustrated by the loss of optimal body functioning. The body presents itself in varied shapes, forms, and at various levels of functioning, and within that the concept of body image can be found.

As explored earlier in the introduction chapter, body image encompasses an individual's self-evaluation based on internal embodied feelings, thoughts and perceptions (Marshall et al., 2014). Glenberg (2010) suggests that embodiment works as a drive-in psychology in the sense that psychological processes are intertwined with physicality, motor and sensory systems, and emotions.

While reflecting on the embodiment of illness and the processes that may be involved in this experience (femininity, sexuality, self-concept), I understood the integration between physical sensations and psychological processes to be a concern belonging to the realms of counselling psychology, due to the latter's holistic approach to wellbeing. Miller (2000) explores clients' experiences of inhabiting their bodies by incorporating life events such as illnesses, suggesting that embodiment is giving voice by the act of communicating internal processes, both organically and psychologically.

The expression of illness through physiological and psychological means has been explored in both medicine and psychology (Aldaz, Treharne, Knight, Conner, & Perez, 2018) and issues of identity are part of such expressions (Oris et al., 2018). Hecht (1993) proposes that illness identity is processed and negotiated in two forms, through a patient's interactions with others and individually in the form of self-reflective practices. Symptoms of visible illnesses (e.g., loss of body parts such as hair after chemotherapy) can be easily identified by others, as opposed to illnesses that involve less obvious physical changes to the patient (Kundrat & Nussbaum, 2003). Nevertheless, Martin (2016) argues that although both visible and invisible illnesses can have consequences for a patient's self-identity, chronic illnesses in particular are often found to trigger self-identity conflicts in patients. This is due to the perceived changes in identity with regard to the patient's physical abilities and role changes in relationships (Martin, 2016).

Oris et al. (2018) examined illness identity in adults with chronic illness by exploring how patients construct and integrate chronic illness into their self-concept through self-report questionnaires (Illness Identity Questionnaire (IIQ)). The IIQ investigates four different illness identity sub-scales: *engulfment, rejection, acceptance,* and *enrichment.* Engulfment and rejection were connected to maladaptive physical and psychological functioning and acceptance and enrichment were linked to adaptive physical and psychological functioning. Through this study, it was possible to conclude that the concept of illness is intimately correlated to self-identity and Oris et al. (2018) maintain that validating patients' issues regarding identity after illness is paramount in clinical settings as a way of offering patients an understanding of how illness impacts their wellbeing and alters their self-perception.

Benyamini (2011) adds that illness perception is only one aspect of patients' overall self-concept, however, such perceptions does not illustrate how patients integrate illness

representation into their identity. According to Benyamini (2011), illness perception serves as a container to organise and store patients' valuable subjective information and beliefs about illness, medical labels (conditions/dysfunctions) and threats to the healthy status. Illness perception is also illustrated as patients' mental representations of illness/health and although it refers mainly to cognitive processes, it also covers some emotional concepts (Benyamini, 2011). Thus, Oris et al. (2018) maintain that to gain insight into how patients make sense of chronic illness, an understanding of how illness is perceived in addition to how individuals view themselves as being a person *with* an illness is necessary.

Carel (2011) explores the experience of illness by suggesting a first-person description of the phenomenon with the aid of Merleau-Ponty's embodied phenomenology. This approach is useful in describing the embodied experience of illness in general as it maintains the focus on human perception. One of the most relevant issues raised by Carel (2011) is the healthy individual's lack of understanding about the subjective experience of illness. This poor understanding – also identified in healthcare professionals – results in a scarcity of descriptive tools that might help patients process their individual experiences. In turn, patients often end up making sense of their illness based on the existing prompts offered by healthcare professionals (Carel, 2011).

The limitation with this medical approach is that the experience of illness becomes standardised and largely understood and described within a medical framework of physiological dysfunction. Carel (2011) argues that the medical approach (disease model) focuses on the lack of body functioning, giving rise to feelings of inadequacy and deficit while promoting difficulties in self-understanding. That framework leaves patients struggling to find their own voices to develop their own illness narrative (Carrel, 2011).

In support of Carel's work, Rodríguez-Prat, Monforte-Royo, Porta-Sales, Escribano, and Balaguer (2016) carried out a thorough systematic review of past qualitative research focusing on questions regarding patients' perspectives of dignity, autonomy and control at the end of life. Three themes emerged from the analysis: *"a) dignity mediated by the loss of functionality, linked to the loss of control; b) dignity as identity; and c) autonomy as a determining factor of perceived dignity, understood as the desire for control over the dying process and the desire for self-determination" (*Rodríguez-Prat et al., 2016*)*. Rodríguez-Prat et al. (2016) highlight the complexities and dynamics of dignity to patients' personal identity,

arguing for comprehensive treatment care plans tailored to patients' individual needs as the means to improve quality of life in illness.

Counterbalancing quantitative approaches to enquiry, the phenomenological approach has been developed as a methodology in itself and, due to the sensitivity of illness as a topic coupled with how patients experience that phenomenon, this methodology has been frequently used in the fields of health/illness and quality of life enquiry (Van Manen, 1990; Moustakas, 1994). Svenaeus (2010) explored the experience of illness within a phenomenological perspective of the vulnerable body through an intricate article. Svanaeus (2010) offers an understanding of illness based on the works of original phenomenologists such as Husserl, Heidegger and Merleau-Ponty. For the purpose of this review, I would like to focus on two pertinent points raised: 'illness and the otherness of one's own body' and 'illness as unhomelike being-in-the-world' (Svanaeus, 2010).

According to Svanaeus (2010), the concept of 'otherness' is a "*foreignness that permeates the ill life"*, which in the context of the self translates into the feelings of 'alienness' and 'unhomelikeness' about one's body in illness. Standing in contrast, the experience of health, or the 'homelike' feelings of being-in-the-world, means maintaining the body's original integrity intact. Svanaeus (2010) argues that the ideas of 'alienness' and 'unhomelikeness', which are connected to difficult feelings about one's body in illness, require an interpretation between the self and the world rather than in relation to the lived body alone. The state of illness or 'alienness' is also closely linked to experiences of physical pain and emotional struggles with loss, for instance (frequently reported by patients), and restricting how people inhabit the world. Although the symbolic meaning of loss – through illness for instance – has not been widely researched, some authors have acknowledged its value (Doka, 1999; Boss, 2009; Pillai-Friedman & Ashline, 2014).

As observed in this section, the process of illness can be psychologically perceived as an intrusion into a well-established lifestyle, deranging the flow of important activities and interests through the loss of physical and psychological functioning, and having a negative impact on overall wellbeing (Bloom, Stewart, Johnston & Banks, 1998). By neglecting bodily expressions of emotions and disregarding somatic experiences, healthcare professionals are not providing a comprehensive wellbeing treatment (Miller, 2000). This leads me to the

exploration of the psychological perspectives on the concept of wellness and quality of life as a result of the intrusion and/or disruption in cancer patients' lives.

2.2. Psychological views on wellness and quality of life

Throughout my review of the literature on cancer, I noted that quality of life can be a widely subjective concept encompassing multiple dimensions and covering a variety of life domains (e.g. family life, work, education, community engagement, health status, to cite a few). Additionally, each life domain can be perceived, valued and prioritised differently by individuals (Bloom et al., 1998). Women's quality of life can be hindered by a number of biopsychosocial aspects during breast cancer, including but not limited to financial difficulties, body image issues, mood disorders such as depression (Reich, Lesur, & Perdrizet-Chevallier, 2008) and sexual dissatisfaction (Schover, 2005).

From a nursing oncology perspective, Tierney (2008) provided an overview of sexuality and quality of life by addressing patients' dynamic biopsychosocial domains, suggesting that sexuality is an integral quality of life domain. In earlier findings, through an assessment of sexual dysfunction at the early stages of cancer treatment, Schover (1989) found significant negative impact on women's sexuality both in terms of physical function and psychological distress, revealing a compelling case for cancer's effect on wellbeing. In support, Schover et al. (1995) considered the psychosocial adjustment, body image and sexuality (relational and sexual domains) of mastectomised women. Based on their findings, Schover et al. (1995) argued that gaining an in-depth knowledge about the definition of what 'sexual satisfaction' meant to individual participants, by looking further into the experiences of orgasms, lone pleasure (masturbation) and levels of libido separately prior and following each intervention, would have been helpful in understanding participants' experience. That kind of enquiry would require a qualitative approach to research and yet, two decades later, in support of Schover et al. (1995), Parton, Ussher and Perz (2015) were still highlighting the limited amount of qualitative research into the experience of physical changes on participants' sexuality.

With regard to the illness-health dynamic in relation to wellbeing and quality of life, an often-adopted definition is one based on the individual's perception of their physical and psychological integrity within their social functioning (Bloom et al., 1998). According to the World Health Organisation (1946), at the turn of the last century, health was defined as *"not*

merely the absence of disease or infirmity but a state of complete physical, mental and social wellbeing". However, for Dodge, Daly, Huyton and Sanders (2012), who have extensively debated the challenges of defining wellbeing within research, the question of defining wellbeing remains unanswered, despite the large number of theories presented to date. Thus, according to Dodge et al. (2012), what constitutes wellbeing is a complex and multidimensional construct, which remains objectively indefinable.

Several decades later, the concept of wellbeing was revisited and the WHO's (2014) definition was changed to *"a state of well-being in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community."* It is apparent that in the space of only half a century, the definition of wellbeing according to the WHO has evolved from being based only on absence of ailment (disease or disorder) to encompassing biopsychosocial domains and also specifically focusing on the importance of individual's autonomy in coping successfully with their own struggles while contributing to the development of their community. It seems as though the concept of wellbeing has become more complex and person-centred with time and as society has evolved.

The concept of effective psychological functioning requires the individual to be able to gain some level of control over life events, developing a sense of purpose and engaging in meaningful and healthy relationships (Huppert, 2009). In the past few years, however, a paradigm shift between an emphasis on dysfunction and a focus on the improvement of positive psychological wellbeing has been increasingly discussed and researched in psychology and health (Seligman, 2002).

Huppert (2009) carried out a review focusing on the positive aspects of wellbeing, supporting the view that psychological wellbeing is a blend between feeling well and efficient functioning. However, Huppert also stressed that wellbeing is not only about feeling good all the time but rather about experiencing vulnerable emotions such as grief and anxiety and having the internal capacity for emotional self-regulation (Huppert, 2009). While considering psychological views on positive wellbeing, a well-disseminated idea is that high pervasiveness of illness is correlated with negative emotional states (Huppert, 2009). The results of a study using mindfulness as a way of improving positive mental states on

physically ill patients showed a significant increase in anti-bodies in comparison with the control group (Davidson et al., 2003).

As discussed in this section, psychological views on wellness and quality of life are subjective and complex due to its multidimensional nature. Women's quality of life can be suddenly jeopardised by a number of psychosocial aspects during breast cancer, including psychological distress (e.g. depression), in addition to issues regarding physical integrity (poor sexual functioning) at the onset of illness. Also as a result of such multidimensional issues, women perceive and respond differently to the mentioned challenges, raising considerations of the need to approach breast cancer patients from a holistic care perspective to aid self-regulation.

3. Reviewing the Literature on Identity Change, Self-image and Sexual Intimacy After Cancer

3.1. The importance of a holistic perspective on cancer in women

Cancer research is vast, and an abundance of knowledge has been acquired throughout history. Although Cancer Research UK was a charity founded only recently (2002), cancer research has been progressing fast since the 1970s when only 25% patients survived the illness. Fast-forwarding, almost 50 years later, the latest statistics show that more than 50% of patients survive cancer for 10 years or longer (Cancer Research UK, 2018). That steep improvement in survival rates called for expanding research in cancer from various disciplines (e. g. oncology, psychology, nursing) and from distinct and complimentary perspectives (e. g. qualitative, quantitative), suggesting that a holistic approach to care was overdue.

3.1.1. Past quantitative studies

Despite the past research that has carried out in a variety of domains related to cancer, White and Butcher (2015) argue that patients' needs with regard to sexual recovery are still not met with enough valuable information. The authors (2015) found that oncologists struggle to address patients' psychological and relational distress, whereas psychotherapists wrestle to help patients manage intricate physical issues relating to sexual dysfunction after treatment. White and Butcher (2015) invited researchers to provide contributions to the knowledge on sexual changes and relationship consequences of cancer and its treatment. Their aim was to gain more understanding of models of integrated sex

and relationship therapies, sexual pain, issues of desirability and arousal in people with cancer, amongst other important topics (White & Butcher, 2015). Sexuality is an important domain nested within the concept of wellbeing and which has a direct effect on quality of life (Boquiren et al., 2016).

3.1.1.1. *Cancer treatment – physical and psychological changes*

While researching psychological views about changes relating to cancer the importance of investigating the biological aspects of illness simultaneously quickly became clear. My reasons for this consideration of the biological changes of cancer are that sexual experiences seem closely affected by overall bodily aspects and functioning or lack of thereof (Al-Ghazal, Sully, Fallowfield, & Blamey, 2000).

Frumovitz et al. (2005) researched a sample of 114 participants, comparing their results from standardised questionnaires in relation to their cancer intervention (radiotherapy, surgery and control groups). Radiotherapy patients' scores showed poorer results with regard to quality of life (mental and physical health), psychological distress and sexual functioning in comparison with controls. The physical changes related to cancer in general and included but were not limited to the following: infertility (Schover, 2008), painful intercourse (Ganz & Greendale, 2007), premature menopause (Schover, 2008), lower libido, vaginal atrophy, poor lubrication (Fobair & Spiegel, 2009), removal of sexual organs (breast) (Kiebert, de Haes & van de Velde, 1991), removal of reproductive organs (womb) (Cleary, Hegarty & McCarty, 2011) and damage to nerves connected to sexual organs (Pillai-Friedman & Ashline, 2014). Such changes may be exacerbated by psychological aspects involving altered sense of body image, fear of abandonment by partners, sexual identity and other concerns regarding the self (Krebs, 2006). Discussion of these sexual difficulties will be embedded within my literature review and addressed throughout the present study.

Wilkinson and Kitzinger (1993) offer their feminist considerations regarding the advice for and treatment of breast cancer in women, arguing that the male gaze on breasts as a sexual object of male pleasure largely affects the experience of breast cancer. In accordance with previously mentioned researchers, Wilkinson and Kitzinger (1993) suggest that the acknowledgement of sexual issues in breast cancer should be brought to light and dealt with openly rather than denied and overlooked by healthcare professionals. In support of Wilkinson and Kitzinger's (1993) study, McKee and Schover (2001) carried out an article

review discussing the commonality of sexual dysfunction amongst cancer patients during and after illness. The article points out the lack of identification of sexual difficulties on the part of medical staff. McKee and Schover (2001) argue that patients are left without specialised assistance with regard to intimacy and stress the need for the incorporation of sexual health assessment and intervention into the existing and overall care plan as a means of attending to sexual rehabilitation for the improvement of patients' quality of life.

Literature on women's sexual health after cervical cancer treatment demonstrates a significant number of patient experiences of sexual dysfunction after treatment, reporting issues with lower libido and decreased sexual satisfaction (Donavan et al., 2007). Amongst the predictors of sexual health were time elapsed since diagnosis, radiotherapy treatment, intimate relationships, vaginal changes and overall attractiveness; these accounted for half of the variables related to sexual health outcomes (Donovan et al., 2007). Also relevant in this study were the findings that a concern about women's sexual health should, according to Donovan and colleagues (2007), go beyond the physiological (vaginal) changes brought by cancer treatment, and that interventions concentrated on sexual recovery should include psychological factors (e.g. self-image and relationships difficulties). In support, Ganz and colleagues (1999) sought to produce quantitative data for marital therapists by exploring the sexuality of a large female sample diagnosed with breast cancer. Findings illustrated a broad range of physical changes (vaginal dryness, ovarian failure, coital pain, premature menopause, etc.), highlighting a negative impact on women's sex life.

'Significant unmet needs' is a term found in the literature and encompasses patients' wishes for open communication about their illness regarding the extent to which cancer impacts various domains in life (e.g. social, financial, emotional, etc.). Soothill et al. (2001) define 'significant unmet needs' as *"those needs that patients identify as both important and unsatisfied"*. Of course, many patient concerns go beyond the service's limitations, so Soothill et al. (2001) explores whether a multidisciplinary approach to treatment would be a better-suited framework in order to meet patients' needs more effectively. The oncology team should include social workers, psychology staff and spiritual advisers. If that is not possible, such professionals should be kept in mind as a support network suggested to patients when drafting a treatment plan for this population (Soothill et al., 2001). Women's physical and psychological struggles during and after cancer treatment should raise the

concern of healthcare professionals' concerns about how to best address patients' difficulties brought on by the changes endured in illness.

3.1.1.2. The importance of a holistic approach to cancer issues

In the past three decades of research, as valuable findings were gathered, the need to develop a more holistic approach to care became increasingly obvious, leading a number of researchers to investigate the biopsychosocial aspects of cancer. Curbow, Somerfield, Legro and Sonnega (1990) investigated the psychosocial domain of cancer research using self-concept as a variable. Depending on the treatment received by patients (e.g. mastectomy), the physical changes subsequent to it can cause changes in self-perception. The extent of these changes depends upon how hostile the method is perceived to be by patients (Curbow et al., 1990). Perhaps surprisingly, more invasive forms of treatment (e.g. lumpectomy) were found to result in less traumatic experiences. A growing body of research on quality of life and self-concept of cancer patients identifies the relevance of self-related variables, so recognising the importance of body image for patients who have experienced body changes (Curbow et al., 1990).

Cleary et al. (2011) explored the sexuality of Irish women suffering from gynaecologic cancer, seeking to gain objective results by applying a series of questionnaires (Body Image Scale, Sexual Esteem Scale, and Sexual Self-Schema Scale, Intimate Relationships Scale and Arizona Sexual Experiences Scale). They aimed to measure issues of self-concept, sexual relationships and sexual functioning. Participants reported unwanted changes in each of these three areas. This study concluded that gynaecologic cancer has a negative impact on women's self-concept, relationships, and sexual functioning, thus suggesting that clinicians should consider a holistic approach in treating patients (Cleary, Hegarty & McCarty, 2011). Similarly, White, Allan and Faithful (2011) aimed to unpick the variables that can cause sexual issues after pelvic radiotherapy treatment. The method used was a structured observation schedule in 69 radiotherapy follow-up appointments over 5 months. Results suggested that physical toxicity was found and sexual difficulties were explored in only 25% of the total medical appointments. During the routine medical appointments only 42% of sexual dysfunction cases were addressed. Results indicate a level of neglect towards the effects of cancer treatment on the patients' sexuality (White et al., 2011).

Using surveys, Krychman and Millheiser (2013) sought to characterise the prevalence and treatment of sexual health issues in women experiencing cancer. Results showed that sexual health issues are often overlooked in clinical practice and that these issues go beyond physiology to encompass sociological and psychological aspects. Amongst the found factors associated with sexual changes are the most common cancer surgery and treatments – chemotherapy, radiotherapy, hormonal replacement, and mastectomy. Participants' shared their concerns about lower libido and lack of sexual desire, reduced capacity to reach orgasms, lack of vaginal lubrication and painful intercourse. Krychman and Millheiser (2013) argued that a limited number of studies exploring the psychological perspectives on this topic were found in comparison to the vast majority of studies carried out by medical staff. They highlighted the necessity to firstly address this gap and secondly to offer a multimodal treatment relating to the sexual health issues that follow cancer diagnosis.

Overall, the reviewed research on women's sexual wellbeing after cancer has revealed a certain level of neglect when it comes to in-depth individual patient experiences of quality of life (Frumovitz et al., 2005). The questionnaires used addressed broad aspects of sexuality experiences, leaving little room for concerns around qualitative data exploration of body image, sexuality and femininity (Kinamore, 2008; Schover et al., 1995). Gaps indicate a lack of integration between physiological and psychological aspects, providing a somewhat fragmented picture of the current status of the care provided to breast cancer patients and leaving unanswered questions about a holistic approach to care.

Given the growing success of current cancer treatment (physical) outcomes, oncologists have recently grown increasingly concerned with their patients' quality of life after treatment. Such concerns involve – but are not limited to – body image, sexual satisfaction and changes in intimate relationships with significant others. By and large, the focal point of past quantitative research has been observing the impact on patients' wellbeing and quality of life in the context of cancer treatments such as chemotherapy, radiotherapy, hormonal treatment and mastectomy. The lack of in-depth research into patients' individual experiences has left a gap, leading to a shift in focus from quantitative to qualitative data gathering and an examination of the link between the physical and emotional issues endured by cancer patients.

3.1.2. Past qualitative studies

As highlighted in the above section, some limitations were found in standardised quantitative approaches to cancer research with regard to the quality of experiences. Beyond the discussed points relating to body image issues, patients' sexual dissatisfaction and changes in intimate relationships, other psychological issues were also identified and are explored in this section from a qualitative standpoint.

3.1.2.1. The psychosocial issues of cancer experience

Willig (2011) draws attention to the dominant discourse surrounding cancer diagnosis, discussing the many ways in which the psychosocial construction of cancer discourse has ramifications on how cancer patients experience illness. One of the many poignant points raised by Willig is: *"One of the many challenges of being diagnosed with cancer is that it requires the person to make sense of the diagnosis and to find meaning in their changed circumstances"* (Willig, 2011, p. 897). Willig (2011) argues that shedding a light on the discursive context in which patients live their cancer diagnosis can contribute to the in-depth knowledge of how they situate themselves within this experience. While discussing the discursive construction of cancer and the meanings attributed to it, Willig (2011) brought up the 'think positively' culture, which is interpreted as people's convictions that hardship will be overcome. When this 'think positively' concept is applied to cancer, it seems to mean that mortality is rejected outright as a potential outcome and that being 'positive' becomes a compulsory position to be adopted. Therefore, acknowledging death as a potential consequence seems to be related to an unhealthy construct when faced with the hardship of illness (Willig, 2011) and potentially raises feelings of inappropriateness in some patients.

Aldaz et al. (2018) explored the psychosocial experiences of cancer patients throughout oncology treatment with curative intent using IPA. Similarly, to Willig (2011), results illustrated cancer patients' different wellbeing domains. The themes found were: "*diminished wellbeing", "perceived role changes in intimate relationships", "heightened awareness of limited time", "new order of priorities, taking things as they come* and the *development of trust in healthcare professionals"*. Aldaz and colleagues (2018) argue that these domains can be strengthened through psychological therapy, as cancer is an illness that affects not only the body but also the mind.

Making sense of cancer diagnosis is an added challenge faced by patients and the existing psychosocial construct of cancer narrative has a direct influence in how patients situate themselves within this difficult experience (Willig, 2011). That raises questions about the ways in which healthcare professionals and patients' approach and communicate about experienced issues (identity, body changes, sexuality, etc.) during treatment.

3.1.2.2. Limited communication with cancer patients

Despite the commonality of sexual issues in women diagnosed with cancer and the persistence of such issues across time reported so far through the literature (Schover, 2005), difficulties in finding a suitable way of addressing these issues remain a hot topic amongst clinicians (Moorey, 2013). Through an investigation of communication issues between ovarian cancer patients and healthcare providers it was possible to notice that although medical staff believed that the majority of patients would experience sexual difficulties due to treatment, only a quarter of doctors and a fifth of nurses engaged in talks on the topic (Stead, Brown, Fallowfield, & Selby, 2003). Cancer patients and medical professionals shared the reasons for this lack of communication and amongst them were embarrassment, poor knowledge, beliefs that it was not their responsibility, and lack of resources to engage in such conversations. Also relevant was that despite these communication obstacles, women expressed a need for the improvement and encouragement of an open communication channel with regard to sexual challenges (Stead et al., 2003).

Cancer and its treatments often cause significant changes and consequently distress to women's sexual wellbeing. Apparent throughout the review of the literature was that regardless of what type of cancer experienced (breast, cervical, gynaecologic, etc.), patients' unmet needs were identified throughout the data (Soothill et al., 2001). Based on the literature reviewed so far, the importance of assessing and communicating biopsychosocial needs of cancer patients (Krychman & Millheiser, 2013) seems of paramount importance in order to provide a holistic care programme that has the patients' concerns at the centre of the formulation.

Traditionally oncologists have focused on the symptoms relating to cancer and its treatment; in recent years, however, treatment effects have been given greater priority. Cases where patients end up with long-term negative effects on sexuality and other areas of wellbeing are the particular focus of such concerns (White et al., 2011). Naturally, oncologists' primary

concern is with patients' organic functioning and cancer survival. However, that leaves a gap for psychological concerns to be discussed when approaching the psychosexual impacts of cancer from diagnosis throughout rehabilitation (McKee & Schover, 2001). Through this comprehensive review of the past qualitative and quantitative literature, I found a gap regarding a holistic/psychological approach to treatment during and particularly after cancer diagnosis and treatment. That gap led me to investigate issues of femininity and sexuality in breast cancer specifically, from a psychological perspective, given that this subject seems to have been somewhat neglected in the past or perhaps conceptualised as less important than patients' sound organic functioning.

3.2. Psychological Perspectives on Women's Identity, Self-image & Intimacy within Breast Cancer

3.2.1. Women's sexuality, body-image and intimacy issues across all ages

Human sexuality is a complex and broad subject involving feelings and perceptions about one's need for intimate touch, the communication of one's sexual desires to partners, the interest in engaging in sexual activities and the willingness to experiment with pleasurable sexual contact and arousal (Lehmiller, 2014). 'Sexual arousal is a term used to describe the physiological and psychological phenomena occurring in parallel with the emotional experience of sexual response' (Chivers & Brotto, 2017, pp. 6). Lehmiller (2017) argues that notwithstanding the breadth of studies investigating the nature of woman's sexual desire in recent decades, the topic still lacks understanding by researchers and therapists. Lehmiller (2017) offers an explanation, arguing that the limited understanding is due to the socially sustained stereotypes about women's sexuality, for instance the belief that women are less sexually aroused by pornography in comparison to men, suggesting that women are not as sexually aroused as men when it comes to visual stimuli. Yet such popular stereotypes and misperceptions regarding the nature of women's sexual desire are not empirically evidenced in research (Chivers & Brotto, 2017) and require thorough investigation.

While considering women's sexuality and its many realms and intricate nature (physiologically and psychologically), I noted that sexuality seems to be a fluid concept that can change and transform in the face of cancer, in many cases leaving patients with poor sexual functioning (e.g. issues with arousal and intimacy). Graham, Boynton and Gould (2017) challenge the current narratives of women's sexual desire and dysfunction in general. Criticisms include the current ways in which these concepts are depicted in the media and

research. The authors argue that sex and desire are multifaceted concepts that deserve an in-depth investigation of their meanings and interpretations. Graham et al. (2017) add that research should dedicate more time and resources to the investigation of under-represented groups (ethnicity, age, sexual orientation). The present status of research on the topic presents a split between the use of medication versus the use of psychological therapies when addressing sexual dysfunction in women. Graham et al. (2017) propose an integration from both perspectives as a way of offering better-informed decision options for women seeking help with sexual issues.

Even though many types of cancer may cause difficulties in women's sexual function and bring intimacy challenges, the described realms of sexuality are closely related to breast cancer patients (Henson, 2002). Breast cancer surgery (mastectomy) and treatment (radiotherapy, chemotherapy, hormonal therapy) can cause a variety of changes in women's bodies and patients respond differently to each approach to treatment. The body changes described by patients are often deep and unplanned, having consequences for women's embodied experiences of self and others with regard to personal appearance and bodily functions from diagnosis throughout recovery (Perz, Ussher, & Gilbert, 2013). The existing body of research indicates that women's experience of breast cancer treatment can cause a range of long-term intimacy issues (Wilmoth, 2006; Anllo, 2000). Amongst the issues found were: lower libido (Andersen, 2009; Arroyo & Lopez, 2012), sexual dysfunction (Schover, 2005; Boquiren et al., 2016) and body image issues (Hungr, Sanchez-Varela, & Bober, 2017).

Body image is a fundamental part of an individual's self-concept and it holds an important position in women's overall wellbeing through its potential effects on physical, psychological and health domains (Marshall et al., 2014). Body image is defined as the individual's perception and evaluations of their physical body's integrity. When considering the concept of body image in the context of female breast cancer, however, women's attitudes and perceptions about the functionality and health need to be taken into account (Hungr et al., 2017). Using surveys to investigate breast cancer patients' issues relating to body image distress, intimate relationships, sexual functioning and overall quality of life, Ganz and colleagues' (1998) findings show that patients experienced poor functioning beyond the acute phase of breast cancer and long after commencing. As a proposed solution, Ganz and colleagues (1998) recommended an increased awareness from healthcare professionals in addressing patients' wellbeing during follow-up of cancer treatment, arguing

that counselling should be made available to patients struggling with functioning during recovery (Ganz et al., 1998). In support, Henson (2002) carried out an extensive review about the impact of breast cancer and its treatment specifically on patients' sexuality. Findings illustrated how mastectomy and treatment impacted negatively on patients' important life domains, including intimate relationships (social and sexual) and psychological and physical integrity.

It is also pertinent to mention some of the reactions and responses experienced by cancer patients with regard to issues in body image and self-concept. Przezdziecki et al. (2013) used surveys (body image, anxiety, depression and stress scales) to research the role of self-compassion as an internal mediating factor between body image and distress in female breast cancer patients. It was concluded that body image issues and poor self-compassion were correlated with higher psychological distress. More recently, Boquiren et al. (2016) researched sexual functioning in breast cancer survivors experiencing body image disturbance; results show pervasive sexual difficulties in patients after treatment and mastectomy. Although the illness-related issues mentioned so far in this review were found across a variety of samples, it is also worth mentioning the findings specifically from age-related studies.

Fobair and colleagues (2006) investigated body image and sexual problems in a sample of young women (50 years old and younger) with breast cancer to check how frequently these issues occurred in the initial phase of treatment. The sample (549 women) used was from multi-ethnic backgrounds that were engaged in committed relationships. Through the results it was possible to identify sexual and body image issues in the first few months after diagnosis in a significant portion of the sample, with half of the sample experiencing two or more body image issues some of the time. The sexually active participants reported considerable body image concerns linked to physical appearance (mastectomy, reconstruction, hair loss, decreased self-esteem and relational difficulties with partners). A quarter of the sexually active sample shared experiences of serious issues connected to sexual functioning (vaginal dryness, decline in mental health state, etc.). Fobair et al. (2006) concluded that sexual functioning and issues related to female sexuality were frequent and had a negative impact on young female breast cancer patients' quality of life.

Also relevant was Kinamore's (2008) exploration of the existing literature on assessment and available support for body image and sexual concerns in young women (up to 49 years

old) with breast cancer as a way of identifying the most appropriate assessment tools and psychological interventions for this population. It was well documented that body image and sexuality-related questionnaires were useful tools in encouraging an open communication about these often hard-to-address issues between young breast cancer patients and doctors. Additionally, taking a multidisciplinary approach to assessment and intervention – including support groups and psychotherapy – offers a collaborative environment for patients' recovery (Kinamore, 2008).

Recently, Hungr et al. (2017) offered some practical recommendations for young (up to 39 years old) female breast cancer patients struggling with self-image and sexuality issues, arguing that clinicians must be able to identify and manage distress-related treatment. Among the recommendations were: physical resistance exercises to improve body functioning; counselling therapy (individual or couple's) for psychological re-adjustment; and exploration of regaining sexual functioning through information pelvic exercises and lubricants. In summary, Hungr and colleagues (2017) suggested some guidance for clinicians involving physical, psychological and interpersonal realms.

Through this review it is noticeable that although body image issues are widely researched in the younger population, there seems to be a limited amount of research on this topic with older women (Chrisler & Ghiz, 2010). Chrisler and Ghiz (2010) argue that body image issues are not limited to eating disorders and are experienced by women of all ages. While considering chronic health problems (cancer), which can cause body image disfigurement and are often diagnosed in older women, Chrisler and Ghiz (2010) discussed how surgery and treatment could lead to the need for psychological intervention in this population. Sexuality is closely linked to body image and addressing concerns of this nature with older patients that have undergone mastectomy should be made routine as a means of exploring how negatively it affects self-concept (Chrisler & Ghiz, 2010). Although conservative surgeries (e.g. lumpectomy, partial mastectomy) are considered a breakthrough in breast cancer treatment, questions surrounding the most appropriate type of surgery for each case remain a topic of investigation. Almeida, Guerra and Figueiras (2012) carried out a systematic review of the literature exploring different types of surgery and found that past studies were based on the premise that mastectomised women show greater difficulties with body image and sexual functioning in comparison with women who had a lumpectomy, for instance.

This subsection has covered issues with women's sexuality, which in itself is complex (Lehmiller, 2017) and it becomes even more intricate to assess and manage after illness (breast cancer) (Henson, 2002). This is due to the variety of domains involved in women's sexuality and its expressions, and the approaches used for treatment (Graham et al., 2017). Body image, sexual functioning and intimacy literature across cancer patients of all ages during the experience of illness was also thoroughly discussed. The issues found were related to cancer treatment in the context of pertinent points with regard to the differences and similarities found across different samples used in past studies. Also relevant to body image and self-concept is the choice of surgery type, which will be explored next.

3.2.2. Mastectomy and reconstruction

Although radical mastectomy (full breast removal) is still a widely used method of breast cancer treatment (Henson, 2002), reconstruction is not available for all women who experience this illness (Al-Ghazal et al., 2000). In some cases, women do not qualify for breast reconstruction and in other cases, despite being suitable for the procedure, some women choose not to have it. Al-Ghazal et al. (2000) carried out a retrospective analysis of the psychological impact of immediate reconstruction (IR) in comparison with delayed reconstruction (DR) in a sample of 121 patients. Results showed that 95% of patients who had (IR) were satisfied with this technique, in contrast to 76% of patients who had DR and would have preferred to have IR. Psychological issues connected to body image, self-esteem, sexual satisfaction, depression and anxiety were significantly reduced in the group who had IR. This study concluded that patients who had IR reported less psychological distress and expressed superior wellbeing compared to the group who had DR. Largely, breast reconstruction was experienced as a favourable surgery in helping women better manage their altered body image and relational interactions after cancer (Al-Ghazal, 2000).

In a similar vein, Gopie, ter Kuile, Timman, Mureau and Tibben (2014) researched the impact of delayed implant and DIEP flap breast reconstruction on body image and sexual satisfaction in female cancer patients, arguing that perspective research relating to the psychosexual changes following various options of breast reconstruction is lacking. Findings suggest that breast reconstruction has a direct positive impact on patients' body image and relationship enjoyment regardless of the chosen reconstruction type.

As noted in the above studies, breast conservation and reconstructive procedures can be helpful in maintaining good cosmetic results for women after breast cancer and

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consequently helping with wellbeing. However, fewer studies have considered the psychosocial results for women who experienced lumpectomy or reconstruction after mastectomy (Rowland et al., 2000). Rowland et al. (2000) explored the role of breast reconstructive surgery with regard to physical and emotional outcomes of breast cancer patients, looking into women's adjustment to surgery. Results from the large sample (almost 2,000 women) using standardised self-report questionnaires measuring body image, physical and sexual functioning and health-related quality of life show that the psychosocial impact on women who underwent lumpectomy was significantly less in comparison to the other surgical groups (mastectomy alone, or mastectomy with reconstruction). Also, by one-year post-surgery, women's quality of life is less likely to be impacted by surgery and more commonly associated with complimentary cancer treatment (Rowland et al., 2000).

Marshall and Kiemle (2005) took a different perspective regarding the research on breast reconstruction; using grounded theory, they focused on the exploration of the relational consequences of breast reconstruction on couple's (patient and partner) sexual functioning. Results show that breast reconstruction is patients' first choice when mastectomy is inevitable and that there is a concern about body appearance. Another pertinent finding of this study regards the lack of information about sexual intimacy individually and as couples, suggesting that partners should be included in the relational part of the assessment of needs in breast cancer patients (Marshall & Kiemle, 2005).

This subsection has provided a brief discussion about mastectomy and reconstruction after breast cancer and how that can impact women's quality of life with regard to overall physical and emotional wellbeing. The following section provides an exploration of women's changed sexuality and issues of body identity in breast cancer.

3.2.3. Changed sexuality and body identity

Changes in women's sexuality and altered sense of self are not an uncommon occurrence in breast cancer patients. Wilmoth (2001) identified patients' altered perception of their sexuality as an important factor in women's wellbeing after breast cancer. Relational difficulties were also stressed in Wilmoth's (2001) study which found that single patients or those engaged in unhappy committed relationships felt less supported through recovery. The findings were split into two main categories: a) losses; and b) influencing pieces. 'Losses' were defined by missing (body) parts – altering sexuality; loss of bleeding – implying

the physical and psychological effects of aging as a result of early onset of menopause; loss of sexual sensation – relating to arousal, orgasm and sexual desires; and loss of womanhood – characterised by the experience of breast cancer as a threat to womanhood. 'Influencing pieces' regarded patients' experiences of managing the illness and was broken down into 'relationships' – referring to support or the lack of it; and 'information control' – regarding the extent to which patients' had control over choice of treatment and information about their illness. Through the identified themes, Wilmoth (2001) reported important findings about sexual adjustment and women's body identity within breast cancer with regard to difficulties in physical functioning, loss of womanhood, relational challenges and the altered sexual self influencing sexuality. Thus, relational support influenced women's capacity for adjustment to illness and treatment.

Also utilising a qualitative method of enquiry, Arroyo and Lopez (2011) conducted an in-depth analysis of the experience of 46 mastectomised women through various stages of diagnosis and surgical treatment. Results showed psychological responses relating to (a) the loss of breast, which is closely associated with attractiveness, self-esteem and intimate relationships; (b) femininity issues of desirability – intrinsically related to the *"feminine position"*; and (c) physical mutilation as a *"hole"* seemingly impossible to integrate. Arroyo and Lopez (2011) suggested that following breast cancer several patients were left with psychological difficulties with regard to their self-worth and changed sense of femininity and argued for the benefits of mental health support to breast cancer patients.

Parton et al. (2015) explored how a group of 16 heterosexual female cancer patients understood and constructed their sense of body and sexuality after cancer diagnosis. By exploring women's experiences through thematic analysis, Parton et al.'s (2015) findings show that participants perceived their bodies as being *"beyond abnormality"*, *"outside idealised discourses of embodied femininity,"* and *"out of control".* Although participants' discourse varied with regard to the management of the challenges faced in cancer, it was possible to identify difficulties regarding femininity and sexuality and the consequences these had for the way women drew meaning from these subjective experiences. In summary, participants felt at odds with their bodies, reporting feeling unfeminine.

In this section, an exploration of women's altered sexuality, body identity changes, and feelings of loss (womanhood, femininity) have illustrated issues with changed sexuality and

body identity with regard to women's adjustment to cancer. These domains of wellbeing were intrinsically linked to cancer patients' overall quality of life. Another important domain (changes in relationships) of wellbeing was briefly visited in this section and will be further discussed below.

3.2.4. Relational changes

Despite the wealth of past studies exploring the quality of relationships and the psychological distress of breast cancer patients, such subjective experiences still lack understanding (Bloom et al., 1998; Breslau, 2003; Ganz et al., 1999) and less attention has been paid to the relational and intimate changes endured by couples during illness. Through a thematic analysis, Gilbert, Ussher and Perz (2013) explored the embodying sexual subjectivity of cancer patients and their partners after illness. Analysis resulted in three main themes: 'dys-embodied sexual subjectivity' – characterised by bodily betrayal, sexual loss, lack of acceptance and mood disturbances; 're-embodied sexual subjectivity' – illustrated by greater sexual confidence, acceptance, exploration of non-coital practices and increased relational closeness; and 'oscillating sexual subjectivity' – demonstrated by a 'shift between dys-embodied and re-embodied states'. The female participants of this research reported dys-embodied sexual subjectivity linked to body image as they were concerned with the physicality of their cancer (scarring, hair loss, etc.), in contrast to the men who were more likely to report issues with sexual erectile dysfunction, for instance. Such gendered responses among participants illustrate normative expectations regarding how sexual subjectivity in men and women is experienced and how men and women expect to be positioned sexually after cancer.

Besides relational and intimate changes, another issue relating to breast cancer that has received little attention in research is the input from ethnic minorities and that is explored in the following subsection.

3.2.5. Ethnic minorities

While looking for breast cancer studies regarding quality of life from broader ethnic populations I was surprised to find a very limited amount of papers considering minorities' experiences. The following research on health-related quality of life (HRQL) explored a variety of physical and psychosocial issues in Latina and African American participants. Its aim was to investigate participants' perceived experiences of the phenomenon as a way of

gaining information to be used in planning culturally sensitive treatment plans. It was found that physical changes had the most impact on HRQL and suggested that psychological difficulties were particularly prevalent in the Latina group (Fatone, Moadel, Foley, Fleming & Jandorf, 2007). Another study exploring health-related quality of life (HRQL) – a multidimensional concept – in a variety of ethnicities (African Americans, Asians, Latinas and Caucasians) reported major concerns with overall health, illness recurrence, psychosocial aspects (children and family), physical integrity, changes in body image and sexual health. Amongst some of the less pressing issues found were poor knowledge of illness, medical care challenges (insurance), length of sessions with physician and issues with culturally sensitive material from healthcare providers to cite a few (Ashing-Giwa et al., 2004). Within the concept of quality of life, sexual satisfaction was found to be a major factor impacting negatively on female patients' experiences following treatment (Ganz et al., 1998).

As discussed in this section, past literature suggests that sexual expression is affected by the onset of cancer and becomes a challenging experience to deal with in terms of relational levels to self (from inside) and to others (from outside). It takes a certain psychological adjustment from patients in order to cope with such challenges (Loaring, Larkin, Shaw and Flowers et al., 2015), and women from different ethnic groups experience changes in quality of life after cancer distinctively (Fatone et al., 2007). What was also noted through this review was how little consideration for ethnic minorities was found in the past literature; only a few studies addressing minority groups within a limited age group were identified (Fatone et al., 2007). Holding that limitation in mind, during my recruitment process, I made an attempt to include ethnic minority participants in my study but I was faced with strong resistance from the organisations I approached and I personally did not come across any individuals willing to take part in the present study.

Given the amount of difficulties experienced by women with cancer found so far in the past literature, it seems a necessary process to investigate how patients adjust to changes and what kind of support is available from a professional standpoint.

3.2.6. *Psychosexual adjustment and psychological interventions*

Although breast cancer is an organic illness that causes a variety of sexually-related physical side effects, psychosexual adjustment through psychotherapeutic interventions should also be considered in the rehabilitation phase (Schover, 2005). Breast cancer survivors reported

sexual morbidity several years after treatment and in particular following mastectomy (Raggio, Butryn, Arigo, Mikorski, & Palmer, 2014). Andersen et al. (2008) carried out a randomised controlled trial (RCT) to check whether the receipt of psychological intervention would help breast cancer patients in coping with their diagnosis. Results showed an improved survival rate in comparison with the control group, which only received a psychological assessment but no intervention.

Using standardised questionnaires, Schover et al. (1995) looked into psychosexual adjustment, body image and sexual functioning of female participants diagnosed in the early stages of breast cancer. Patients had prompt breast reconstruction surgery or breast conservation and mastectomy treatment. Sexual Attractiveness Sub-scale of Body Esteem (BES) after interventions were measured, and findings illustrated that a significant number of participants encountered poor psychosexual adjustment to cancer clinical interventions. The authors concluded that local surgery had a small degree of psychosexual impact in female patients. Patients treated with chemotherapy were left with long-lasting psychosexual disorders such as painful intercourse, vaginal dryness and poor body image. More recently, and also using a quantitative approach to investigation, Marcus, Garret, Cella, Wenzel, Brady et al. (2010) carried out randomised controlled trials (RCTs) across 21 hospitals and clinics assessing patients' recovery rates through self-administered questionnaires. The questionnaires assessed the following points – distress, depression and sexual dysfunction and personal growth. Results reported a small yet significant improvement in outcome results in the treatment of sexual dysfunction using phone-counselling therapy at the early stages of breast cancer recovery. Rodrigues et al. (2012) found that women who underwent radiotherapy reported being left with negative impacts on sexual satisfaction and wellbeing. Results also found that women were left with low sexual desire and dyspareunia (painful sexual intercourse), negatively affecting their sexual satisfaction and wellbeing.

Since its beginnings in the 1970s, oncology research has progressed greatly, offering insight into the psychological distress experienced by patients through the development and improvement of psychotherapies, such that we have reached a stage where healthcare professionals (other than psychology staff) receive basic training in identifying distress and listening to patients' concerns (Moorey, 2013). Through a review of the literature, Moorey (2013) found that psycho-oncology treatment has three distinct phases: "*1) defining patients' needs, 2) developing and demonstrating effective interventions; and 3) disseminating*

psychological skills." These phases seem to have served as the foundation for the current model developed by the NHS in the UK (Moorey, 2013). The proposed model suggests a step-up care plan and within that care plan, four levels of specialisation can be found (NICE, 2004). The first step consists in assuring that all healthcare professionals possess sufficient skills in relaying sensitive information using empathic communication, have the ability to identify psychological distress and possess basic psychological support skills. Training for healthcare professionals in basic psychological intervention skills linked to problem solving composes the second step. The third step regards a more formal approach to psychotherapy, where counsellors are involved in the treatment to deliver interventions. The patients presenting with more complex and severe cases are stepped up into the fourth and final step, to be treated by psychiatrists and health/clinical/counselling psychologists (Moorey, 2013). Although this model provided valuable guidance regarding how to identify cancer patients' needs, Moorey (2013) argues that at present clinicians are not yet able to effectively apply such skills.

In 2017, Matthews, Grunfeld and Turner explored the efficacy of psychosocial interventions on breast cancer patients through a systematic review of the existing literature. Evidence shows the efficacy of cognitive behavioural therapy (CBT) mostly in the improvement of depression, anxiety and quality of life. Other interventions (mindfulness-based stress reduction, support groups, psycho-education, etc.) were also found to be successful in treating issues connected to body image, self-esteem, sexual functioning and sleep disturbances as well as anxiety, depression and quality of life. Pillai-Friedman and Ashline (2014) suggest a treatment framework (PLISSIT) for clinicians and based on female breast cancer patients who experienced sexual losses (sexual self-schema) and 'disenfranchised grief' as a consequence. Disenfranchised grief is defined as *"grief related to their loss [...] a kind of grief that is precipitated by a loss that cannot be socially sanctioned, openly acknowledged, or publically mourned",* causing a decline in patients' quality of life. The PLISSIT framework is composed of four levels (permission giving, limited information, specific suggestions, and intensive therapy) and was developed by Annon in the late 1970s to address breast cancer patients' sexual difficulties. PLISSIT encourages breast cancer patients and their partners to openly discuss sexual issues with their clinicians; it provides general written and electronic resources with relevant information regarding sexual health recovery. Counsellors and sex therapists can offer individually tailored information about sexuality recovery and lastly, if the previous steps are not sufficient due to the complex

nature of needs, then intensive therapy delivered by highly specialised psychology staff can be implemented. In summary, this grief model provides a framework for healthcare staff to identify, validate and treat sexual losses as a means to moderate losses and re-stimulate eroticism.

The data available on psychosexual adjustment and intervention relating to breast cancer found been predominantly compiled using standardised measures in large samples of patients and mostly in the early stages of treatment and recovery (Andersen et al., 2008). Several studies enquired about overall sexual satisfaction regarding frequency of full intercourse, overlooking the wider spectrum of sexual intimacy that women view as important for relationships and wellbeing (Schover et al., 1995; Boquiren et al., 2016). Another important area raised in this subsection related to issues encountered in the doctor-patient relationship when it comes to addressing the psychosexual adjustment of women patients. T will be addressed further in the following subsection (Anllo, 2000).

3.2.7. Communication between doctors-patients

The role of healthcare providers in general (oncologists, nurses, sex therapists, etc.) is paramount for a sound communication of sexual issues in specialist-patient dynamics. Henson (2002) stresses the necessity for clinicians to promote an open channel of communication with breast cancer patients. This includes exploring issues of a sexual nature relating to cancer treatment and, when applicable, suggesting individual and couple's psychological therapy as a way of helping patients in managing self-concept and relational struggles. Andersen (2009) adds that sexual wellbeing after the recurrence of breast cancer could benefit from increased awareness from clinicians.

Despite the available options for women to preserve eggs and embryos prior to engaging with cancer treatment, Schover (2005) argues that largely patients reported not being offered the necessary information by healthcare professionals, and therefore they invariably risked becoming infertile. Pillai-Friedman and Ashline (2014) stressed the important role of physicians, arguing that the denial of sexuality may contribute to an increased sense of loss in patients. As discussed previously in this chapter, a significant number of women report difficulties with sexual functioning as a consequence of breast cancer treatment, also spoke about the importance of recovering sexuality for their wellbeing (McKee & Schover, 2001); however, what was also found is that women struggle to start such conversations with their

doctors (White et al., 2011; Collins et al., 2011). Shifren et al. (2008) found that despite the difficulty in addressing distressing sexual issues, female patients are more likely to bring up their concerns than their clinicians. This raises questions about the responsibility of healthcare providers to encourage talks about sexual difficulties while incorporating this into their routine assessment of patients' needs (Ganz et al., 1998; McKee & Schover, 2001; Marshall & Kiemle, 2005; Krebs, 2006; Collins et al., 2011).

Past research on breast cancer reports that an average of 50% of female cancer patients experience cancer treatment-related sexual problems. The problems raised are of a physical (painful intercourse, scarring, vaginal dryness), psychological (stress, body image) or relational nature (loss of intimacy) (Perz, Ussher, & Gilbert, 2013; Reese, Bober & Daly, 2017). Reich, Lesur and Perdrizet-Chevallier (2008) identified two important criteria in maintaining breast cancer patients' quality of life, namely, the quality of information delivered by healthcare professionals and the maintenance of open communication with patients about the presentation of the illness, and information about how to cope with difficult feelings that may come with the cancer diagnosis. Despite the wide variety of sexually-related issues reported by breast cancer patients, compelling evidence shows the difficulty healthcare professionals have in identifying and openly assessing patients' concerns, leading to a gap in the healthcare service (Male, Fergus, & Cullen, 2015).

4. Summary and Research Question

In summary, this chapter reviewed the available literature regarding the concepts of illness, wellness and quality of life within women's identity change, self-image and sexual intimacy after cancer. Amongst the points explored and discussed were the physical and emotional changes related to cancer (body image, sexual functioning, relational issues, etc.), the psychological perspectives on the process of illness, wellness and QOL within breast cancer, and the importance of taking a holistic perspective on cancer treatment in women.

The gaps in the existing literature were discussed in the body of this chapter and included communication barriers between doctor-patients; limited research on older women's experience of sexual challenges after cancer; the majority of the research stemming from a medical perspective; an apparent lack of integration between knowledge gained from a psychological and physiological perspective; and fewer studies investigating ethnic minorities in comparison to the majority of research based on white participants. Despite

having made attempts to reach ethnic minorities in my research, unfortunately I could not address this group because both individuals and charities met me with rejection. The other mentioned gaps will be addressed in my study.

Due to the gap found in attending to psychological needs as promptly as physiological needs of patients during breast cancer treatment, I aim to present results from a qualitative perspective that can be applied in conjunction with the existing body of (largely) quantitative and medical research. My intent is to narrow down this gap between psychological and medical disciplines by merging psychosocial domains in the overall care plan of breast cancer patients as a way of offering a holistic approach where an open channel of communication between patients and doctors is facilitated. Among the group of women willing to take part in my study, I found a sample of mostly older women (average 50 years old).

My research question is *'how do breast cancer patients experience (physically & emotionally) their femininity and sexuality during the rehabilitation phase?'*

3. CHAPTER THREE. METHODOLOGY

"We don't see things as they are.
We see things as we are."
Anais Nin

Overview of the Chapter

In this third chapter I will discuss my rationale for adopting a qualitative paradigm, more specifically Interpretative Phenomenological Analysis (IPA). This chapter describes the essential features of my methodological considerations based on my ontological and epistemological positioning, and my use of strategic and embodied reflexivity throughout the study. A comprehensive description of how my research was carried out can also be found in this chapter. I will be outlining my explanations regarding the theoretical foundations of the chosen methodological framework (IPA), primarily based on Jonathan Smith's (2009) suggestions.

1. Interpretative Phenomenological Analysis (IPA)

1.1. Overview of IPA

Interpretative Phenomenological Analysis (IPA) is a qualitative approach to research founded by Jonathan Smith in the mid-1990s. It derives from the philosophic inquiry of Husserl who recommended phenomenologists to *"go back to the things themselves"* – meaning that research should concentrate on the participants' experiences themselves, yet through the lens of the researcher's interpretation of the given experience (Smith, Flowers, & Larkin, 2009). It takes a stand that valuable knowledge can be acquired by exploring and understanding an individual's experiences instead of building knowledge based on the foundation of theories. IPA looks into the quality of an individual's major life experiences (Smith et al., 2009). The researcher's interpretation of the data is an important part of the IPA process due to the researcher's own reflections being acknowledged but also seen as a directly influential factor in the findings (Willig, 2013).

IPA is a methodology widely used and recommended in the fields of health and counselling psychology and it is often applied to investigate the nature of illness and how illness is perceived physically and psychologically (Smith, 1996). Additionally, IPA has been

increasingly used to explore sexuality and identity development (Smith, 1999). Smith's recommendation was a strong influence while considering IPA for my study.

1.2. Rationale for adopting IPA

After careful consideration, IPA was chosen as the most appropriate methodology for this study as the purpose of that methodology is to provide participants with the chance to explore their individual experiences (Smith et al., 2009). In the case of the present study, what is being explored in-depth are my participants' experiences of femininity and sexuality in the context of physical illness (breast cancer) through my interpretative investigation.

IPA allowed me to obtain valuable insights into the nature and quality of my participants' embodied relational experiences (Willig, 2013). Unlike quantitative approaches, where researchers work towards either proving or refuting a hypothesis, I analysed the data by bringing my own interpretations about my participants' lived experiences based on my chosen humanistic framework in combination with my strategic and embodied/personal reflections on the topic (Smith et al., 2009).

As per Smith and colleagues' (2009) suggestions, I chose IPA due to its methodological suitability to the epistemology of my research question. Before choosing IPA, however, I considered two alternative qualitative approaches; Grounded Theory (GT) and Discourse Analysis (DA). Those will be discussed in detail under section 4.6 in the context of my rationale for adopting a qualitative paradigm.

1.3. Criticism of IPA

Perhaps the biggest critique of IPA has come from Giorgi (2011) through an 'open letter' in the format of an journal article in which Giorgi has a discussion with Jonathan Smith regarding IPA's methodological procedures. Giorgi (2011) accused Smith of confusing phenomenological concepts and of approaching the method with a reductionist view in comparison with the method's original phenomenological and hermeneutic theoretical frame, as presented by Husserl and Heidegger (p. 206). In defence of Smith, Finlay (2011) suggests that the phenomenological enquiry should be regarded as such if it contains an in-depth description of the lived phenomenon. Finlay (2011) also argues that the researcher must reflect on any potential impulses to bring in any elements which are not founded by the data and that they are transparent about it their own biases.

Giorgi (2011) continues his critique by adding that IPA may not be as scientific a method as other approaches because it cannot be replicated in order to ensure its reliability. Further, he adds that the 'non-fixed methods' or 'flexible' approach or lack of articulation of clear steps in the application of IPA procedures is detrimental to its scientific status (Giorgi, 2011). In response, Smith defends that IPA does have a suggested fixed procedure in terms of holding a series of steps, but the steps are not fixed in a particular order and various researchers may approach the data differently and flexibly (Smith, 2010).

2. Rationale for Adopting a Qualitative Research Paradigm

2.1. Ontology, epistemology and methodology

Psychological research is informed by a set of beliefs commonly known as a paradigm. A paradigm is a conceptual framework based on ontological, epistemological and methodological assumptions about the world. In this sub-section I will be discussing how my ontology and epistemology defined my choice of methodology (IPA). Ontology refers to beliefs about the nature of the world whereas epistemology concerns the theory of knowledge. In practical research terms, considerations about "what is there to know" or type of knowledge to be gained is known as ontology while concerns about how "how can we know about something" or how knowledge can be gained is known as epistemology (Willig, 2013). Epistemology and methodology are driven by ontological beliefs. Epistemology investigates the relationship between knowledge and the researcher during the research process. In another words, it refers to how the researcher gains knowledge about a given phenomenon. Methodology is concerned with how researchers go about finding knowledge in a systematic way. The researcher's ontological and epistemological positioning is what drives the system used to gain knowledge (e.g. surveys, experiments, questionnaires, interviews) and different methodologies vary in degree of subjectivity.

During my literature review, I came across a number of studies on a similar topic, which used different and objective paradigms to gain knowledge. I found a study by Fobair and colleagues (2006) where surveys were used to measure body image, sexual activity and sexual problems in an ethnically diverse and large population sample of women aged fifty and younger, diagnosed with breast cancer. In their survey, questions required a yes/no reply alongside the scaled indication about frequency of the experience. Results show that participants experienced difficulties with body image and sexual functioning after being

diagnosed with and treated for breast cancer. A few limitations were found in this quantitative approach, however, what caught my attention the most was the fact that the researchers viewed having a face-to-face interview as a potential limitation for the study's results. According to Fobair et al. (2006), that would be due to the fact that participants would be less inclined to share their concerns given the sensitiveness to the topic. Although that is a valid methodological concern, while reflecting on my chosen methodology, I thought of the face-to-face interview as strength of my approach rather than a limitation. I believe in my capacity to create a bond, despite the briefness of the meeting, during the interview process, and that this would bring the participants closer to me and therefore more willing to discuss their experiences.

My study instead concerns the subjective quality of my participants' experiences of femininity and sexuality after mastectomy and the ontological position of the presenting study is relativist. Willig (2013) states that in that position the world is not viewed in an *"orderly, law-bound place that realists believe to be"*. Instead, my attention is focused on the various possibilities of interpretations of the phenomenon (Willig, 2013). I see my position as the researcher to be of paramount importance in the process of constructing the findings based on my perceptions and while staying close to my participants' accounts. My view is in contrast to those of a realist approach, which instead maintains that although the researcher is an important part of the research process, they are not granted the status of authoring the findings but rather are seen as the ones who uncover evidence in the data.

According to Willig (2013), there are essentially two main and opposing perceptions of reality or epistemological stances available and they range broadly from realist to relativist and others "in between". Realism is commonly used in traditional science, which approaches research to find empirical, objective and measurable 'truth' or facts about reality. It believes that a reality exists and this reality is objective and independent of human beliefs and behaviour. A truth exists even if it is not yet uncovered and it is context-free. This perspective is found within a quantitative paradigm of research. At the other end of the spectrum we find relativism and that is the search for meaning in the individual experience. Relativism believes that reality is contextual and that multiple constructions of reality are not only possible but also influenced by relationships and experiences; sustaining that each individual has their own reality. It is an epistemological perspective found within qualitative research paradigms. In between epistemological stances of realists and relativists,

phenomenology is found. In phenomenology, experience is constructed rather than fixedly determined and 'real' experience is dependent in the individual's experience of a phenomenon, granting phenomenology a malleable stance.

My epistemological stance is phenomenology. In that position, I am maintaining that meaning is drawn from an individual's unique experiences and based on how they construct their reality (Willig, 2013). This seems to be the best-suited alternative available with regard to the phenomenon I am interested in and my research question is *'how do breast cancer patients experience (physically & emotionally) their femininity and sexuality during the rehabilitation phase?'*. Through my chosen methodology (IPA), I am aiming to gain an in-depth understanding of how participants make sense of their individual and subjective experiences in that context. I am approaching the data using a qualitative methodology (IPA) to seek knowledge by observing and interpreting the rich lived experiences of my participants' context (Willig, 2013). Qualitative, phenomenological enquiry is concerned with the knowledge gained from an idiographic perspective, which encapsulates participants' emotions, ideas and perceptions of the quality of their experiences (Larkin, Watts, & Clifton, 2006).

In the next three sections of my rationale for adopting a qualitative paradigm, I will be exploring some key phenomenological ideas as a way to further clarify my research positioning.

2.2. Intentionality

"According to a phenomenological perspective, it makes no sense to think of the world of objects and subjects as separate from our experience of it" (Willig, 2013). Willig (2013) argues that all objects and subjects in the world manifest themselves as something and that is what forms or embodies the reality of it. What varies is the view being held by whoever perceives the phenomena and those views are based on an individual's context, positioning and *"mental orientation"* such as judgments, various degrees of understanding, emotions, purposes, etc. That concept is known as intentionality (Willig, 2013).

Intentionality in the case of this study refers to the quality of my participants' internal processing regarding their external experiences of femininity and sexuality in the context of illness. The phenomenological enquiry views reality as being shaped by individual

experiences of the world around them (Willig, 2013). It sustains that human perception is not separate from meaning but rather perception is intentional and forms the experience itself. Phenomenological positioning maintains that different people may experience and perceive the same phenomenon in the 'same' environment in completely varied ways (Willig, 2013). These varied perceptions of the world around us are subjective and driven by intentionality, meaning that a person's conscious intent creates representations or meaning of experiences (Giorgi, 1997).

Merleau-Ponty argues that the quality of intentionality is experienced through the person's body and it refers to the state of consciousness, as we are consistently aware of something in the world around us. Intentionality is often referred to as *'about-ness'*, meaning that the object of consciousness does not need to be an actual physical object; rather, it can be an individual perception, fantasy, phenomenon or any other structure that represents intentionality (Smith, 1964).

2.3. Hermeneutics

Hermeneutics is the theory of interpretation, which seeks to understand human existence (van Manen, 2014). Hermeneutic phenomenology believes that human existence in the world holds meanings through an individual's experience of their cultural and social events and that the individual and their world cannot be disambiguated (van Manen, 2014). Thus, it aims to shed a light and reflect on an individual's meaningful experiences through the researcher's interpretations of those experiences (Smith et al., 2009). According to Finlay (2011), originally there were two main schools of thought regarding the type of phenomenological enquiry. Husserl developed the first, and it focuses on the essential description of phenomenon while taking into consideration personal reflexivity: establishing a way of looking, researching and understanding the world in a non-mathematical way and aiming to capture individual human experience (Hollway, Lucey & Phoenix, 2012). By contrast, Heidegger's views refer to the idiographic parts of an experience, which is to be interpreted within a theoretical framework and taking situational factors into consideration. Heidegger presented lived experiences in the form of an interpretative process rather than a descriptive one as presented by Husserl (Smith et. al., 2009).

As a researcher, I used double-hermeneutics, which situates me completely at the centre of the interpretative process, requiring me to ground my interpretations in my participants'

accounts. This process requires an increased attention to be paid to the reflective practice within the research process. Double-hermeneutics accounts for my interpretation of my participants' shared phenomenon by the meaning-making process of their meaning-making while using the theoretical framework of phenomenology (Finlay, 2011). Finlay (2011) also explores the different levels of interpretation and suggests for instance that emergent themes comprise the first level of interpretation, where the researcher reports a description of the original experience. The layers of interpretations that follow that initial step, however, are based on theoretical concepts and are more interpretative. Double-hermeneutics involves therefore both a description and an interpretation. I have also kept detailed notes about my reflective process (Finlay, 2011).

2.4. Bracketing

Bracketing is understood as the acknowledgement and suspension of the researcher's own judgment and preconceived ideas about how the world functions while they instead turn their focus to the investigation of the phenomenon experienced by participants (Smith et al., 2009).

Smith and colleagues (2009) stressed two essential parts of analysing and describing participants' experiences: attending to the researcher's own assumptions of the phenomenon being studied and the suspension of attitudes towards the phenomenon. A number of authors disagree with Smith and colleagues and instead defend the idea that a complete suspension of pre-formed ideas and assumptions is neither necessary nor possible. However, they add that it is necessary for such ideas and assumptions to be openly acknowledged and reflected upon in relation to how these may affect the data analysis and interpretation (Willig, 2013; Frost, 2011; Dowling, 2007).

Bracketing was a useful tool in keeping me attentive to my previous knowledge and beliefs about the topic and about what the results might have been. It assisted me in focusing on the interpretation of the data, allowing me to remain with my participants' voices (Finlay, 2011). This concept is highlighted more in depth in the reflective sections of my analysis diary.

2.5. Alternative qualitative methods

This section presents my rationale for choosing IPA over other qualitative methods of analysis. Grounded Theory (GT) and Discourse Analysis (DA) were also considered for this research. In the case of the proposed study, IPA is concerned with how individuals make sense of specific phenomenon within a given context (Willig, 2013), as opposed to GT, which is a framework interested in developing a theory based on a given social phenomenon (Starks & Trinidad, 2007). GT takes a 'top down' approach to analysis, meaning that the research starts with a specific question and then through data analysis (coding) constructs a theory (Starks & Trinidad, 2007). In contrast, IPA is a 'bottom up' processing method, which is concerned with the rich description of a small group of participants' shared phenomenon – sexuality and femininity after mastectomy in this particular case (Willig, 2013). Thus, in IPA, knowledge of phenomenon is developed through commonly shared human experiences in an exploratory fashion (Willig, 2013).

DA is an approach interested in the relationships between verbal communication and pre-existing discourses, that aims to gain knowledge of how individuals use language to construct and perform identity and relationships (Starks & Trinidad, 2007). This stands in contrast with IPA's nature, which focuses in the participants' perceptions of a particular experience. Whilst the use of language is considered in IPA enquiry due to the analysis of the transcripts, its main focus is gaining a rich description of lived experiences (Starks & Trinidad, 2007) rather than focusing more directly on language constructs (Spencer, Ritchie and O'Connor, 2003).

In support of my choice for IPA, a significant body of research has explored successfully the issues of health and illness using phenomenological enquiry (Smith et. al., 2009; Brocki & Wearden, 2006) and difficulties relating to patients' sense of identity and sexual intimacy, which have arisen from the results. Brocki and Wearden (2006) argue that IPA has been strongly established in the area of health psychology. According to Smith, Flowers and Larkin (2009), one of the main research areas for IPA is sex and sexuality, due to the sensitiveness of the subject. One particular study by Lavie and Willig (2005) about the experience of 'inorgasmia' for instance, brings to light an understanding of the issue of living with a sexual condition and how that is conceptualised in the context of women's sense of self, affecting their self-image and self-identity. Although GT, DA and IPA converge in qualitative methodology, seeking an interpretative approach to address enquiries about

meaning, when applied as research methods, diversions arise regarding the way in which the researcher frames the question, recruit participants and collect data (Starks & Trinidad, 2007).

Following my research on the best methods to be used in addressing my research question, IPA seemed to be the most suitable fit given the nature of the information I was hoping to gain – in-depth, personal accounts of a small group of women who shared the lived-experience of a phenomenon (mastectomy after breast cancer) and the meaning attributed to that. My type of questioning stands in great contrast with the DA enquiry on how knowledge, meaning and identities are constructed through language use, or the GT exploration of how social structures affect social interactions. After all the above-mentioned considerations, it was concluded that given the nature of this study's enquiry, IPA would be a better fit than GT or DA due to its features.

3. Methodological Considerations

3.1. Validity

Although concepts of validity and reliability are often associated with quantitative data analysis, assessing the quality of qualitative studies is also possible and in fact essential to ensure robustness of findings (Smith et al., 2009). Yardley (2000) suggests a set of four criteria, which can aid qualitative research in ensuring validity. These are 'sensitivity to context', 'commitment and rigour', 'transparency and coherence' and 'impact and importance'.

Yardley suggests that' 'sensitivity to context' can be demonstrated in a number of ways. To name a few, it can be identified through the researcher's ability to situate the research within a socio-cultural context, by thoroughly exploring the existing empirical literature in the topic (Yardley, 2000) or alternatively by the very choice of IPA as a methodology due to its idiographic feature as a way to keep the study close to the participants' perspectives (Smith et al., 2009). Thus, and highly relevant to counselling psychology, 'sensitivity to context', can be illustrated through the researcher's appreciation of the relational interactions with their participants during the interview process. That takes place through the researcher's ability to show empathy, and to negotiate intricate power play between the theory expert (researcher) and the experiential expert (participant) (Smith et al., 2009).

The second and third criteria involve the researcher's competency in establishing 'commitment and rigor' and 'transparency and coherence' respectively and they relate to the common expectation for competency as in any type of research (Yardley, 2000). In IPA, 'commitment and rigour' can be demonstrated in the data collection, which depends on a suitable sample being recruited by the researcher. Additionally the researcher's 'commitment' to the analysis process through a complete and in-depth data immersion is also seen as part of 'commitment and rigour'. In other words, the interpretation of participants' sense-making of their experiences requires of the researcher a great commitment to being closely attentive to the accounts provided as a way to remain as close to the participants' meaning as possible (Yardley, 2000). 'Transparency and coherence' refer to the researcher's honesty about all the steps taken during the research and write-up processes, in an open and logically connected fashion and in keeping with the underpinnings of the chosen methodologies (Smith et al., 2009).

With regard to 'impact and importance', Yardley refers to the relevance of the written work and whether that offers a valuable contribution to the reader and/or wider community such as health workers or policy makers (Smith et al., 2009).

Additionally, Yardley (2000) also stresses the importance of *"the relationships between researcher and participant, including the balance of power, affect the collection of data and meaning therein"*.

3.2. Sensitivity to context & commitment and rigour

As a way to ensure sensitivity to context and commitment and rigour, I made sure that amongst those participants willing to take part in the study, only the women who were in the recovery process of breast cancer treatment were accepted. While attending to the potential ethical issue of safeguarding of my participants, prior to the interview, I carried out a phone risk assessment to check the participants' past and present mental health wellness. Calling my participants before the actual meeting for the research interview was also a helpful way of having an initial contact in order to start building a rapport.

It was a great concern of mine as to whether my knowledge on the topic was sufficient prior to the interview, however, in the rare cases when participants spoke about very intricate aspects of their treatment, I did not hide my confusion and requested a clarification. My

transparent approach to seek such knowledge had two functions. Firstly, that was my way of familiarising myself with what the experiences meant for each of them and secondly, that was my way of prompting my participants into talking further about their experiences.

During the course of the interviews I was conscious of my position as a researcher from a heterosexual orientation, a middle-class woman coming from an educated background, which was very similar to my participants' background. Thus, I was also aware of the differences between us and in how these would be integrated in the research relationship. Unlike my participants, I am a South American, don't have a diagnosis, and a single woman. My detailed reflections on context are explored more explicitly in my embodied/personal reflections section.

I was genuinely curious about my participants' embodied experiences and it was important to me that they felt my empathic stance towards them. This was my concern not only as a way to create a safe environment to welcome participants to talk but also as a way to show I respected the meaningful journey they had been through and the privilege I felt in being trusted by them. I was also mindful about interpreting the data based on my participants' meaning-making rather than manipulating the results according to my own concepts (Smith et al., 2009).

3.3. Transparency and coherence

My commitment to transparency throughout the research process includes my commitment to keep a reflective diary regarding the context of the obtained sample (Willig, 2013), a clear report of the research process and its methodology and an appropriate comment on the data acquired in terms of verbatim quotes of my participants (Smith et al., 2009).

3.4. Impact and importance

With this project, I am aiming to add a relevant contribution with regard to bringing attention to the need for counselling psychology in the treatment of cancer care. In my discussion chapter and based on my results, the reader will be able to find a through exploration of the need for counselling psychology provision in cancer care units, from diagnosis to recovery.

4. Reflexivity

4.1. Strategic reflexivity

The key role of methodological/strategic reflexivity in IPA has been stressed by a number of researchers (Willig, 2013; Finlay, 2011; Frost, 2011) and while formulating my research question, I kept in mind the fact that qualitative research methods refuse the pre-formulation of a hypothesis.

IPA specifically seeks to carry out the enquiry from an idiographic perspective. That positioning matched my interest as a researcher in the detailed experiences of my participants and their meaning-making process, which is very similar to the practical/clinical enquiry. During discussions with lecturers, supervisor and colleagues, I explored how I could go about finding the knowledge I was seeking. My research question came about during my epistemological reflections and considerations about the assumptions I had on the topic of femininity and sexuality after a significant physical body change. I was looking into capturing what were the feelings, perceptions and thoughts of these women. I was curious about what it was like to go through such an experience, and what it meant to them in their context (social and psychological). I was not interested in causality but rather concerned with the quality of their experience of femininity and sexuality after having their breast removed.

The research question could have been explored using a different theoretical approach and my reflections on these options can found under the section 'alternative qualitative methods'. My chosen study design (IPA) was essential in constructing the findings, and the steps proposed by Smith and colleagues (2009) facilitated my interpretative engagement with the data. The way in which meaningful codes and themes were extracted and clustered in a step-by-step fashion helped me greatly in integrating findings based on my participants' accounts within and then across data (Brocki & Wearden, 2006). Further, having my preconceptions acknowledged and presented in a transparent fashion was an essential factor in keeping the study robust (Willig, 2013). I expected to find potential relational difficulties regarding sexual wellbeing, but I was open to finding it otherwise and I was aware of keeping an open mind instead of getting caught up in my own assumptions. I assumed that femininity and sexuality would be more relevant than I had originally anticipated. Although I found a few gendered themes related to sexuality and the position of women in relationships that was not the main finding of my project, as I discuss in more depth in my findings and discussion sections. Throughout this project, I was aware that my personal

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characteristics would influence and shape the analysis and its meanings but, as is the nature of IPA, such assumptions were explicitly discussed. I agree with Willig (2013) regarding the difficulties in remaining outside the subject being studied. However, my commitment in acknowledging biased assumptions about the participants' accounts, based on my own stereotypes, was considered at the outset and this commitment was monitored through a reflective diary.

During the literature review, I came across an extensive number of studies stemming from a biological medical field. Commonly, oncologists' main focus lies in the patient's organic functioning and more specifically in this case, cancer survival. McKee and Schover (2001) argue that this leaves a gap for psychological studies relating to the psychosexual impacts of breast cancer from the moment of diagnosis and throughout recovery. As breast cancer treatment fast evolves, granting recovery and longevity to patients, oncologists have become more focused on their patient's wellbeing during recovery (Siegel, Naishadham & Jemal, 2013). A gap in the literature from a qualitative standpoint and the apparent segregation between medical doctors and psychological practitioners seems to create a need for the integration of both perspectives to complement each other, creating a holistic approach to treatment. The lack of psychological support in breast cancer care units was a dominant theme that came up amongst my participants when they talked about coping and care during rehabilitation.

Although I have no direct experience of sexual difficulties relating to breast cancer, I believe that this is a highly pertinent topic for the female population. White and Butcher (2015) have recently published a call for contributions on the issue of sexual relationship consequences of cancer and its treatments in the journal *Sexual and Relationship Therapy*. They suggest that sexual rehabilitation needs for patients affected by cancer are still a relatively under-researched field. I hope that my academic knowledge about the subject and the framework in which I have mostly chosen to operate in my practice – humanistic – will inform the research process and its outcome. My role in the research process was limited in the sense that I had little personal experience of the chosen topic. While considering a few potential difficulties I could have encountered while researching the topic, I wondered how the participants viewed me and my hope was that I would be seen as a sounding board, a non-medical person with whom they felt at ease exploring concepts relating to their sexuality and femininity following breast cancer. To achieve that outcome, I attempted to initiate a strong

rapport from the moment I rang them in the triage call but also while interviewing them. I used my humanistic skills of attentively listening to their concerns and keeping the interview non-directive in order to answer the research question.

In terms of axiology, I am taking a critical positioning, whereby I admittedly predict and expect that my value biases are an influence in the research and its outcomes (Ponterotto, 2005). Regarding the rhetorical structure, I will also be adopting a critical approach and therefore the rhetoric of this study will be presented in the first person in a personalised manner (Ponterotto, 2005). As a way of adding rigour to my study, during the interview process I kept on checking my understanding by paraphrasing my participants' accounts in order to stay true to their experience.

4.2. Personal / embodied reflexivity

The experience of the body in qualitative research, and more specifically in phenomenological enquiry, is central and grounded in theoretical philosophy. Embodied reflexivity focuses on the researcher's embodied felt-sense and the non-verbal communications between the interviewer and interviewee (Finlay, 2006). According to Merleau-Ponty, experience is determined by the individual's physical perception of events and in which the body functions as the link (Smith, 1964). In support of Merleau-Ponty's ideas, Seymour (2007) also defends the idea that the body is central to qualitative research, arguing that *"ethnography involves visible bodies: bodies bearing messages and messages bearing bodies".* Following that line of thought, it seems unnecessary and even unavoidable to take away the researcher's own identity and felt-sense in the course of research analysis. Embodied reflexivity therefore functions as a way to *"go back to the things themselves",* in other words to focus on the conscious experiences of the world within phenomenology and beyond (Smith et al., 2009). As part of my personal/embodied reflective practice, I consider how my personal experiences may have shaped this study. All my participants asked me whether anybody close to me had experienced breast cancer, and when I confirmed that I had not, that seemed to have invited them to speak to me in depth about their own lived experiences of illness both physically and psychologically as one intertwined and meaningful theme.

As a way of introducing myself to give some context about my involvement as a researcher, I will describe my biological, psychological and social context. I am a Latino American

woman from Brazil, descendent of Northern and Western European families. I am in my middle thirties, heterosexual, cisgender, physically and psychologically healthy and single. I come from a matriarchal family with a larger number of female members than male members. As such, the issues concerning the feminine world have always been in the forefront of my mind and a common topic of conversation. I come from a culture in which despite sexuality being very explicit in society, it has also been historically treated in a conservative way. As a consequence, exploring feminine sexuality has been even more of a taboo, making me even more curious and inquisitive about the topic.

My involvement with counselling psychology began about a decade ago with personal therapy and a search for a clearer purpose in my life while seeking directions and an improvement in my own quality of life. As my knowledge of wellbeing evolves and broadens, I am becoming increasingly curious about all realms of people's lives – physical, psychological and spiritual. However, for the purpose of this research I will focus only on the physical and psychological sides. Counselling psychology is concerned with people's wellbeing and functioning and I believe in covering my clients' physical and psychological realms holistically. Thus, as a practitioner, I believe in adopting a humanistic approach to assessment and treatment as a way to stay close to my clients' way of making sense of their world. During my clinical experience, I have sought to broaden my skills as widely as possible by adopting multiple theoretical orientations such as humanistic, psychodynamic, CBT, integrative (cognitive analytical therapy and schema therapy).

Although I was never diagnosed with cancer or any other serious illness that could have impacted my sexuality or femininity, in my clinical work I have come across women who have struggled with the experiences of cancer in relation to their femininity and sexuality. This includes women who have had types of cancer other than breast – womb cancer for instance. Additionally, I had two aunts from my father's side who had breast cancer and one cousin who died in 2017 as a consequence of generalised cancer.

As a researcher-practitioner, I wondered whether there were some assumptions made by participants that were not voiced during our meeting and for that reason I asked for feedback about their experience of taking part in the study. Their feedback will be included in my discussion section. During the course of data gathering, I also reflected on the fact that I look healthy and have long hair. The trigger of my reflection about my own body was the

fact that my first participant was still bald from chemotherapy treatment and another one had just started growing her hair back following treatment. I was concerned about how my appearance might have had an effect on my participants' perception of who I was. Based on that concern, I decided to wear my hair up for the interviews as a way of containing the physical aspects, which could potentially distance me from my participants. In addition to that, during the interviews, I was also conscious about wearing clothes that showed no cleavage for the same reason mentioned above.

As a researcher-practitioner, I revitalised my core humanistic values, particularly empathy and acceptance. There seems to be a gap in academic and clinical fields with regard to how intrinsic parts of one's creative life are neglected during a life-threatening event and how professionals do not always attend to those parts once the patient is out of risk. Once their lives are no longer at risk, these women are left with devastating effects on their self-concept and struggle to re-adapt to 'normal' life. The latest statistics from Cancer Research UK (2016) found that over 50,000 women are diagnosed with breast cancer in the UK each year. The female survivorship rate from breast cancer for 10 or more years in 2010–11 in England and Wales was 78%. I am personally interested in this topic due to its relevance for the field of Counselling psychology. The importance of the integration between psychological and medical assessment for the success of a patient's recovery was found to be of paramount importance in promoting sexual wellbeing, consequently increasing the client's quality of life. Accounting for the embodiment of breast cancer and the sexual issues arising from it, a phenomenological perspective would be strongly recommended. The medical community can be informed and benefit from qualitative findings being added to the existing and meaningful quantitative research.

5. Sampling and Recruitment

5.1. Recruitment inclusion and exclusion criteria

It was imperative that my participants were female, above the age of 18 years and had undergone a mastectomy after a diagnosis of breast cancer. My decision to focus on the female population was due to the fact that breasts are often regarded as an important part of the female sexual identity.

5.2. Purposive sampling

I approached this study using purposive sampling. This refers to the method of choosing selective participants through a common 'lived experience' based in shared characteristics of a population to fit the study's objectives or the phenomena being studied (Smith et al., 2009). The term 'lived experience' refers to the individual's embodiment of socio-cultural and historical context (Frost, 2011). The utilisation of a purposive sampling strategy provided scope for the participants who were recruited to fall within a specific central part criterion, ensuring, therefore, that I gained a homogenous sample (Smith et al., 2009). The criteria were that the participants had undergone a mastectomy and were in the recovery phase of breast cancer. However, as the research progressed, I realised that femininity and sexuality was not a priority in the mind of those still fearing cancer as a threat to their lives. I then decided to extend the main criterion to participants who were willing and robust enough to talk about femininity and sexuality, but within a time period of over five years since having had a mastectomy.

While addressing some practical considerations, I came across the suggestion of Smith et al. (2009) and Langdridge (2007) about the average sample size for doctoral students. They consider anything between four and ten participants as sufficient and that varies according to the nature of the research question. Data saturation was also a criterion which was addressed and that relates to the point where research results begin to be repetitive (Wertz, 2005). Femininity and sexuality are very broad concepts and before choosing the sample size I also consulted with my supervisor. I was advised to keep a sample of eight participants as a way to manage the time constraints of my project effectively. Thus, Smith et al. (2009) also suggest that in IPA purposive sampling is the best option, as IPA aims to investigate the experiences of a homogenous group rather than achieve generalised findings.

5.3. Recruitment

Initially, I intended to recruit participants through Cancer Research UK and Macmillan Cancer Research, amongst other charities, by posting adverts (see Appendix 7.1) within each service's support group with the help of the local clinical staff. However, I was met with significant resistance. Instead, the recruitment process occurred mainly through placing adverts on boards and in lifts at my university but also using my local hairdresser and nail bar. That was challenging to begin with, but as I acquired my first two participants, the process rolled out in the form of snowball sampling. Through the initial phone call to check

their suitability for the study, I managed to build a good enough rapport with participants whereby they felt comfortable to discuss their experiences with me.

My study employed a multiple recruitment strategy: I approached Cancer Research UK charity shops, online forums – Mumsnet and Netmums, Facebook groups – BreastCancerCare, The National Theatre during a show about breast cancer and I also advertised within the university's Social Sciences building and in my local nail parlour. The same flyer was circulated in all these avenues, offering further information should anybody be interested. Additionally, some participants offered to share the flyer within their circle of contacts. I will introduce and describe my participants individually and in detail in my fourth chapter - analysis.

5.4. Sample

The recommended sample size for an IPA study is of six to eight participants. This is with a view to prioritising the quality of the data gathered rather than the quantity (Smith et al., 2009). I chose a sample of eight participants based on the quality of depth of my analysis and following the IPA standards for a small homogenous sample. My participants were aged eighteen and above, heterosexual and currently sexually active – either in a committed or a non-committed relationship setting with one or more partners. I had an initial phone triage, in order to ensure not only that participants fitted the criteria, but also to ensure their psychological robustness prior to sending invitations about partaking in my study. Participants who were suffering from severe mental health issues were excluded from the study to avoid causing any harm by asking potentially sensitive questions. My participants did not have a history of mental health illness prior to their breast cancer.

5.5. Initial contact

Potential participants contacted me via email directly after coming across the research ad. Following that initial email, I then set up a phone triage in order to ensure the psychological robustness of my participants and also to carry out a risk assessment comprised of five main questions regarding their psychological wellbeing and the stage at which they were in their lives (see Appendix 7.2). During this phone triage the participants also had the chance to clarify any questions about the extent of their participation, the nature of my study and also personal questions about my interest in the topic. Once participants confirmed their intention to part take in the research project, I then set up interviews either in a room at the university

or, in a couple of cases, at their home. My supervisor was kept in the communication loop and was involved throughout the process.

6. Data Collection

In accordance with IPA requirements, the interview schedule (see Appendix 7.5) was designed in such way that the chosen phenomenon was explored broadly to begin with and then slowly narrowed down to focus on the research question. The exploration employed IPA's focus on the participants' lived experiences and the meaning created by participants.

I personally collected the data via individual, open-ended and semi-structured interviews with my participants. Interviews lasted approximately 60 minutes. I used a recording app (Voice Record) to record the individual interviews. An additional digital recorder was also used to record the interviews as a backup device. All the interviews were kept safely in an encrypted file in my personal external hard drive, which was kept in my home office.

Prior to the actual interviews, however, I conducted a pilot interview with one participant and that interview was not included in the study. The aim of the pilot interview was to test the quality of my interview questions with regard to language appropriateness, eloquence, but also to gain the participants' feedback regarding the quality of the questions. The pilot was a valuable opportunity to exercise my interview skills and ability to follow the interview schedule with some level of flexibility, while allowing space for what the participant was bringing into the interview process. Listening back to the pilot interview was useful in terms of improving my interview skills and in trying to manage sufficient silence for participants in a non-demanding manner. Also, based on feedback from the pilot, I learned that the original interview schedule felt slightly repetitive, as a few questions were very similar in content. I managed that by changing the questions going from a broad to a narrower enquiry and also by adding more prompts such as "can you elaborate further please" or "tell me your story on that". I felt more confident and better prepared for the actual interviews after the pilot.

I explored my participants' in-depth accounts of the phenomena through a series of 10 to 15 semi-structured, open-ended and flexible questions, including a few prompts to invite participants to elaborate further on their answers. The non-directive interview schedule (see Appendix 7.5) began with a question regarding the beginning of the process of breast cancer diagnosis in order to build a rapport with each participant, going through the potential

changes experienced, to finally culminate in the actual research question exploring the feelings and meanings attached to the experience of sexuality and femininity during and after cancer treatment/surgery. In other words, the interview process began talking about the individual's experiences of cancer in broad terms, gradually narrowing it down to more in-depth accounts, finalising the interview with the exploration of their current wellbeing as the first step into the debriefing process in an organic fashion (Smith et al., 2009).

6.1. Location

Regarding the location chosen, out of the eight interviews conducted, two took place at the participant's home and the remaining six took place at the university's Social Science building in a quiet, private and small room. Each location was chosen according to the participant's need for a confidential, convenient and safe space where they felt most comfortable. All locations took into consideration safeguarding precautions and were conducted individually and in person.

6.2. Pre-interview

During the initial phone triage, which lasted approximately 15 minutes, participants were informed about the research, about me as the researcher, about their rights to remain anonymous, their right to withdraw, the level of involvement required, any potential upsets that could be caused indirectly due to the intimate nature of my questions, and the appropriate contact details should they require any psychological support following the interview process. Participants were also reminded that the interview would be audio-recorded for approximately 60 minutes, depending on how much they wished to share.

6.3. Interview

An interview schedule of 10 to 15 questions and prompts was developed. The semi-structured interviews differ from structured interviews in the sense that the interview is not determined by the questions, but rather guided flexibly by it. The semi-structured interview schedules respected the participants' accounts rather than imposing a rigid structure. This flexible approach to the interview in turn provided a space for me to follow my participants' lead while developing a stronger rapport as I was able to gently explore and probe further details from my participants (Smith & Osborn, 2015). Although most authors suggest semi-structured interviews as the most suitable method of enquiry in IPA (Langdridge, 2007), Smith and Osborn (2015) argue that is not always appropriate.

While considering other alternative methods of enquiry such as email dialogue, I came to the conclusion that having one face-to-face, semi-structured interview was more in line with gaining a richer and deeper account from my participants. That choice was reinforced by my chosen practice's framework –humanistic, which is the backdrop of all my clinical and non-clinical relationships within counselling psychology. I briefly shared the interview schedule with my participants during the introduction to my study and a few minutes before beginning the interview. Together we went through the questions and I was concerned about being very transparent with regard to what I was asking of them and about how much or how little they could share with me. My participants were required to read, complete and sign and date the consent forms, after which I also signed and dated.

6.4. Closing the interview

Each of the eight interviews was drawn to an ending according to what felt appropriate for each participant and as they sensed they had shared all there was to say about their experience. The limit agreed between us was 60 minutes and that boundary was respected and gently maintained. At the end of each interview, participants were given a debrief sheet (see Appendix 7.6) which contained contact details for any psychological support services they might need following the interview process. The debrief sheet was read and discussed together, to address participants' individual needs and queries. At the end of this process, all participants were thanked for their time and valuable contribution to the study and the majority of them had enquiries about the study but also about me personally, which I was happy to address. My participants' feedback about the interview is available in my reflective diary.

Table I. Participant's information

Participant	Means of recruitment	Demographics	Mastectomy Outcome
FEM01 (Abbi)	Charity shop ad	40, White British, married	Reconstructed from own tissue
FEM02 (Barbara)	University ad	75, White British, married	No reconstruction
FEM03 (Carol)	University ad	45, White British, married	Unsuitable for reconstruction due to previous health issues
FEM04 (Deanne)	Nail bar ad	60, White European, widowed and then open relationship	No reconstruction
FEM05 (Elena)	Word of mouth	50, White British, married	No reconstruction
FEM06 (Fiona)	University ad	60, White British, married	Silicon implant
FEM07 (Gabi)	University ad	55, White British, married	Silicon implant
FEM08 (Heather)	University ad	50, White British, married	Silicon implant

6.5. Ethical Considerations & Practice

First and foremost, my priority in relation to ethical considerations was about the wellbeing of my participants. In order to protect participants' identities and their confidentiality, I replaced individual names for fictitious ones, as well as altered their ages and any personal identifiable demographic details. Participant anonymity was carefully considered and

ensured throughout the research process by keeping electronic and non-electronic files safely stored. Some of the quotes were not included as an exemplar statement in the analysis chapter due to my concerns regarding my participants' anonymity. A series of safeguarding procedures were followed to ensure this project was ethically appropriate. Prior to beginning the research, ethical approval was sought and acquired by City University of London Ethical Committee and in accordance with the BPS Division of Counselling Psychology 'Professional Practice Guidelines', The BPS 'Code of Ethics' (2009) and the HCPC Standards of Proficiency for 'Practitioners Psychologist' (2012).

Each participant received a phone call prior to the interview to explore the research methods, procedures and any other queries they may have had. In that initial phone call, I carried out a risk assessment to ensure my participants' wellbeing and suitability for the project. In the triage phone call, I explained to all participants that I would be asking intimate questions about their sexuality and femininity following their mastectomy and I stressed that it was important for them to reflect on whether this was a good time to be revisiting painful memories. I reminded all participants that the thesis would be submitted as part of my doctoral portfolio, that research papers could be published, and that after that point it would not be possible to withdraw their anonymous data from publication. Interviews were scheduled according to participants' availability and readiness to engage in the study and they picked the interview location (their home or university). At the time of the interview, I shared the interview schedule (see Appendix 7.5) with the participants and read it out with them. Prior to the interview, participants received an information sheet (see Appendix 7.3) followed by a consent form (see Appendix 7.4). These were discussed verbally with participants and I provided them with signed copies (consent form) prior to the start of the interview. Following the guidelines suggested by Smith et al. (2009) I engaged in a reflective process with participants exploring the potential impact of my questions on their wellbeing as they could have potentially felt distressed after the interview. I did not experience any issues regarding my participants' wellness following the interview.

Lastly, I offered a debrief form (see Appendix 7.6) containing details about the study, along with my own and my supervisor's contact details. Alongside the debriefing, I offered my participants the opportunity to chat about how they were feeling after the interview. That process was not time bound and any concerns, queries or feedback were welcomed warmly, respectfully and in a supportive fashion. Some participants felt tearful during the interview

and I managed their feelings by listening to their concerns and containing feelings in an empathetic and kind fashion while keeping in mind that I was with them as a researcher rather than as a therapist. I was diligent in ensuring that free and reduced fee professional counselling services (BPS and Mind) could be accessed should the participants require this service following the interview. The relevant contact details were also stated in the debriefing sheet.

6.6. The researcher-participant relationship

Prior to the interviews, I was curious about how to balance the researcher-participant relationship and also about how that relationship would unfold. At the end of the interview schedule, I added a question about the participants' reasons for taking part in the study. The reasoning for doing so was to elicit some actual information about the participants' feelings regarding the research process and their experience of me. Amongst some of the useful feedback received was the following:

"Well, I saw the notice in the lift and thought: 'nobody's ever asked me'. I mean I've spoken with friends, one or two friends who've had breast cancer, but nobody ever asks you – 'how you feel about it?'"

(Elena, line 355)

"… I think this is such a major change to people's lives, that I think understanding the, you know, where you are going, is so useful, that I thought it would be very useful research…"

(Fiona, line 427)

"… nobody asks us this, nobody does, so that's why it's really great you're doing it. Not even ourselves. We don't even ask ourselves, so and I think it's really interesting."

(Gabi, line 447)

"I feel good now, actually part of the reason I did this, I felt talking it through would be a kind of way of, not closure as such, but just cathartic a bit… To help people feel this matters, the emotional side of things as well as the physical side…"

(Heather, line 395)

In the first couple of interviews I felt some tension about staying in the role of researcher. I was fully aware of my therapeutic skills and in how they could be used in that setting while respecting the ethical boundaries of staying in the role of researcher rather than that of therapist. However, as the remaining interviews unfolded, and I gained valuable feedback from my participants, I felt more at ease to engage with them while staying at the edge of their experiences and refraining from using interventions as I probed them to elaborate further in their accounts (Kvale & Brinkmann, 2008). I was also aware of the ethical transgression issues proposed by Kvale & Brinkmann (2008), where the researcher is advised to manage their empathy in order to prevent participants from over-sharing and then later regretting it.

7. Analytic Procedure

7.1. Transcription

According to Smith and colleagues (2009), the transcription process should include all words spoken by the participant and the researcher, including breaks in sentences, overlaps in speech, repetitions, pauses, and hesitancies. Although Langdridge (2007) supports the idea that transcribing the data verbatim is important, he argues that adding finer details of accounts is not the main focal point in a phenomenological approach. Having the transcription phase as of paramount importance for the process of data interpretation and description, I decided to follow the suggestions of Smith and colleagues (2009) and transcribed the data accurately and without any grammatical corrections. The digital audio-recordings were kept in an external hard drive in encrypted files safely locked away in my home office.

7.2. Transcripts

Following a lengthy transcription phase, the coding process was initiated and comprised four stages as per Smith et al.'s (2009) methodological suggestions. The first step was about the initial exploration of data during which I carefully read and re-read the individual transcripts a number of times while listening to the interview's audio file. During that first step, I began noting a few brief observations and reflections in the right margin of the transcript as a way of acquainting myself with the data. Secondly, my initial notes were then labelled '*Analysis Notes'* and were divided into three distinct categories, namely descriptive, linguistic and conceptual. These categories were colour-coded across the data and the key located in the line 1 of the transcript. Thirdly, I began labelling phrases and sections of the transcript under

the title '*Emergent Themes'* in the right margin of the *Analysis Notes*. This initial clustering of themes was listed from in-depth examination of the themes and that was when I started finding similarities, which created initial categories/themes by the combination of two to three codes. The labels were based on behaviours, feelings, concepts, beliefs and discrepancies in accounts. I also paid attention to repeated language, things that surprised me and things that my participant explicitly told me to be important, or if anything reminded me of theories. In the fourth step, I chose the most relevant *Emergent Themes* and started identifying relationships between them according to conceptual similarities, which in turn made the data more coherent. After that I labelled each category while describing why I was clustering the sub-themes under each major theme and an individual table of themes was created in order to make the data clearer. Once the table was created, it made it easier for me to move themes around and make sense of it as a whole. Several emergent themes were dropped during the clustering, as they were very similar to each other or were not significant enough, having appeared only once across the whole interview. The table of themes can be found in Appendix 7.12.

7.3. Analytic strategy

Smith and colleagues (2009) suggested a set of IPA analytical methods in the form of four steps and stressed the flexibility with which such guidelines were to be applied (p. 79). The four steps suggested by Smith and colleagues (2009) are step one - reading and re-reading, step two - initial noting, step three – developing emerging themes and step four –searching for connections across emergent themes. In the step one, the researcher is expected to be immersed in the original data while listening to the audio recording of each interview. In the step two, the researcher begins the detailed analysis of the data, exploring content descriptively, linguistically and conceptually in order to capture the essential quality of what has been expressed in the text and while staying close to the meaning attributed by participants. In the third step, the researcher begins searching for emergent themes by looking into keeping the complexity of data while aggregating the details in to a reorganisation of the data. In step four, the researcher looks maps out a coherent and connected net of how the themes fit in together as a whole (Smith et al., 2009).

In Appendix 7.7 an excerpt from *FEM_01 Abbi's* transcript can be found, and it illustrates all the steps of my analysis process. In the transcript it will be possible for the reader to identify the different steps of my analysis by searching each individual column. The initial transcript

had the 'line number' column on the left most part of the document, followed by the second column - 'original transcript' and then the 'analysis notes' column was added subsequently, which composed by descriptive, linguistic and conceptual notes. Once I finished the transcripts initial 'analysis notes', the final two columns were added 'emergent themes & sub-themes', which was then followed by the addition of the final column 'major themes.' As the analysis process evolved, I used a white board and to refine the numerous initial codes into narrower and meaningful overarching themes.

I understand that it is not common practice to include previous literature within the presentation of an IPA analysis, so I will present an account of how this literature was brought into my analysis process. The transcripts were analysed completely separately and without reference to previous literature, therefore my insights were not shaped by it during the analysis process. I wove the references to the past literature into the analysis section during the write up process, in order to provide the reader with a sense of how the outcomes of my analysis related to previous research. My data analysis process was based on my own interpretation of my participant's lived experiences and in line with my chosen therapeutic approach – humanistic, combined with reflective practices (strategic and embodied) on the subject (Smith et al., 2009).

7.4. Mind maps

The mind maps were created by hand using a white-board, which also enabled me to move themes around freely while trying to make sense of the clustering process. The clusters received an initial label, but that changed throughout the clustering process. A sample of my initial and final mind maps can be found in Appendix 7.10 and 7.11. Following Smith et al.'s (2009) proposal, during the analysis process I was mindful about engaging with the data in a fragmented way by analysing individual words and themes as a way to stay true to my hermeneutic stance, but also to engage with the data as a whole across all participants.

7.5. Tables

The tables available in Appendix 7.11 illustrate how I came to the description of my major themes supported by the sub-themes. In terms of validity, I was concerned about how frequently the themes were recurrent across the data. This was also relevant in terms of remaining truthful to my participants' accounts and to the methodology's idiographic proposal (Smith et al., 2009).

4. CHAPTER FOUR. ANALYSIS

"So, I think that's me having come full circle in a lot of ways really."

(Fiona, 331)

Overview of the Chapter

In this fourth chapter, in order to offer the readers some relevant context to participants' experiences, I will firstly introduce each participant. Secondly, I will present a table with the major themes and sub-themes that emerged from the data analysis. Thirdly, I briefly describe each theme, followed by quote's analysis from participants' interviews and lastly a quote illustrating those. My analysis resulted in three major themes – *Ill Self; Vulnerable Self; Coping Self* – and nine sub-themes – *shock, pain, body changes, control, uncertainty, other's gaze, warrior, comparing losses, recovering*. It will be possible for the reader to see a demonstration of the overlaps amongst themes, thus relaying divergences and convergences in my participants' shared experiences.

1. Introduction to the Participants

The below summaries provide some contextual information regarding my participants' basic demographic details (pseudonym, approximate age, broad nationality and sexual orientation) and also their relationship status, rough dates of diagnosis and treatment, mental health status, and psychological and physical treatment received during illness and in recovery.

Abbi is a 40-year-old Caucasian, British heterosexual woman from the UK and she has been married for many years. Abbi was diagnosed with an aggressive type of breast cancer and ended up having a mastectomy in 2014. She underwent chemotherapy and radiotherapy and at the time of our interview she was recovering from a second occurrence of breast cancer. Abbi had a breast reconstruction. Abbi was in receipt of peer group support at her local hospital, which was facilitated by nurses. Abbi reported feeling emotionally held in attending monthly meetings.

Barbara is a 75-year-old Caucasian, British heterosexual woman from the UK and has been married for several decades. Barbara had a mastectomy back in 2012 and did not need radiotherapy or chemotherapy. Barbara opted for not having a breast reconstruction.

Barbara was not engaged with any psychological services and reported feeling well supported by her family. Barbara reported feeling good as she recovered incredibly well from the mastectomy and never had any issues in relation to it since the end of treatment.

Carol is a 45-year-old Caucasian, British heterosexual woman from the UK and she has been married for several years. Carol had her mastectomy a couple of years prior to our meeting and she received chemotherapy and radiotherapy. At the time of our interview, she was still receiving some treatment (injections). Carol was not suitable for breast reconstruction due to prior health concerns. Carol requested a referral from her oncologist for individual psychotherapy specific to her breast cancer treatment. She felt she could benefit from therapy in order to re-adjust to her life after breast cancer. She shared that the biggest difficulty she had during that experience had been re-adjusting back into "normal life".

Deanne is a 60-year-old Caucasian, northern European heterosexual woman. Deanne was married at the time of the diagnosis but unfortunately, she became a widow during her recovery. She described having been considering a relationship with a man she was dating at the time of our interview. Deanne was diagnosed with breast cancer in the 1990s for the first time and then again in 2005 and ended up having a mastectomy then. She received radiotherapy since the surgery and was on hormonal treatment at the time of our interview. Deanne opted for not having breast reconstruction. Deanne never sought any emotional support and at the time of her mastectomy she had a very supportive husband. She shared that the biggest difficulty she had during that experience was losing her husband.

Elena is a 65-year-old Caucasian, British heterosexual woman from the UK and she has been married for several years. She had her mastectomy in 2002 and finished her chemotherapy treatment the following year. Elena did not have a reconstruction. Elena did not receive any psychological support at the time of diagnosis and neither had she by the end of her treatment. Subsequently, Elena reported having felt anxious which led her oncologist to refer her to a couple of sessions with a counsellor within the service. Elena said that ending the treatment caused her to feel suddenly anxious as she was trying to re-adjust to her life after the treatment. She was referred to a psychiatrist but reported not having had a positive experience as she said that he was looking for the trigger to her anxiety rather than managing the ongoing changes in her life.

Fiona is a 65-year-old Caucasian, British heterosexual woman from the UK and she has also been married for several years. Fiona had her mastectomy in 2015 and finished her radiotherapy and chemotherapy a year later. She had a breast implant and needed further surgery to correct it. Fiona had a total of four individual sessions of counselling at her local charity service. Fiona shared that she was looking into returning to psychotherapy as she felt she had been ruminating on past issues unrelated to her cancer diagnosis. Since her diagnosis, Fiona had decided to retire in order to look after her own wellbeing and that of her family. Fiona had a formal diagnosis of depression – unrelated and prior to her breast cancer experience.

Gabi is a 60-year-old Caucasian, British heterosexual woman from the UK and she has also been married for several years. Gabi was diagnosed in 2014 and had a mastectomy the following year. She did not have reconstruction. She also underwent chemotherapy and radiotherapy. Gabi did not feel the need to engage in psychological support at the time of the diagnosis and has not done since. However, Gabi was concerned about how she would feel once she was no longer going to be monitored by the breast cancer clinic. She found her appointments to be reassuring and after enjoying a five-year cancer-free period she will no longer need regular follow ups.

Heather is a 50-years-old Caucasian, British heterosexual woman from the UK and she has also been married for several years. Heather was diagnosed with breast cancer in 2016, received radiotherapy and ended up having a mastectomy a few months after the diagnosis. Heather had an implant after her mastectomy. She received a brief period of couple's psychotherapy and individual counselling at her local charity. Heather had been recovering well from her surgery but said she was still within the five-year follow-up window. Heather shared having been diagnosed with mild depression following the end of her treatment and surgery. She added that this was due to some significant bereavement in her family during the recovery phase. Heather was not prescribed any medication and her GP suggested the use of an online self-help resource, which she found somewhat helpful.

Table II: Framework of master themes and sub-themes

Master Themes	Master Theme I: **'Ill Self'**	Master Theme II: **'Vulnerable Self'**	Master Theme III: **'Coping Self'**
Sub-Themes	***'Shock'*** *(Sudden)*	***'Control'*** *(Surrendering/Taking)*	***'Warrior'*** *(Survival Mode)*
	'Pain' *(Psych / Physical)*	***'Uncertainty'*** *(What might happen)*	***'Comparing Losses'*** *(Other losses)*
	'Body Changes' *(Self-image)*	***'Other's Gaze'*** *(Self-concept)*	***'Recovering'*** *(Functioning)*

2. Major Theme I: '*Ill Self*'

The *Ill Self* major theme emerged from participants' shared feelings, beliefs and behaviours around having a new role established as they were notified of a surprising and serious change for the worst in their wellbeing – going from being healthy women to abruptly becoming breast cancer patients.

2.1 Sub-theme I: 'Shock'

All participants unanimously mentioned *'shock'*. They all described their initial response to breast cancer diagnosis using that powerful word, even though a few were sure that the test results were not going to bring good news.

In the extract below, Abbi describes reacting with immense surprise when she was first told about her diagnosis. Initially, when she found the lump, she'd dismissed it, as *"it could have been an abscess".* It was as if she could not have possibly believed that her new reality was being unwell. Sudden changes in mood are a common occurrence during illness diagnosis and treatment, with patients reporting a range of feelings such as shock, anxiety and fear. The changes in mood often reflect the illness stage and are influenced by a number of challenges experienced throughout sickness and its treatment (Keitel & Kopala, 2000). Strong emotional reactions were found in relation to women's loss of healthy identity.

While analysing the language used by my participants at the initial stage of diagnosis and treatment, I was struck by how frequently women used a highly medicalised language to describe their first experiences of breast cancer (Langellier & Sullivan, 1998).

"…When I was first told, it was a huge shock because I never for a moment though what was wrong with me was gonna turn out to be breast cancer. […] And then the following week they told me it was stage 3, aggressive triple negative, which is a quite difficult one to get on the top of." (Abbi, 4/18)

Barbara also described feeling shocked by her breast cancer diagnosis, sharing how she tried to reconcile her feelings of shock with the perception that she might have contributed indirectly to the development of her breast cancer through the continuous use of hormone therapy overtime.

"I felt shock, but I had in a sense, erm, I had been taking hormone replacement therapy for about 14 years." (Barbara, 24)

Deanne was receiving the diagnosis for the second time in her life, but it also came as a shock. In contrast to Abbi, however, Deanne was also concerned about not being able to conceive again (she has a daughter from a previous marriage) and having her future plans interrupted abruptly. Her role as a mother and as a wife was jeopardised. Deanne seems to have found herself in the position of suddenly having to abdicate from her felt-responsibilities as a mother and as a wife to concentrate on the illness (Adams et al., 2011).

"Yeah, the last time I was forty-five and err, just married again, and he was ten years younger than me, so we really wanted to have children, so we had like so erm, it was a shock…" (Deanne, 4)

Fiona detected the lump and shared *"I felt my lump, I'm a doctor I knew it was breast cancer"*. However, following the exam results, she was unpleasantly surprised to discover that the illness had spread fast and that meant she'd need to have her cancerous breast removed. That sudden change in her health and in her professional role came as a shock to her.

"…I actually was not expecting it to have gone into the lymph nodes, that was a shock, that was a real shock to find that it had spread already and that I would need a mastectomy…" (Fiona, 48)

Unlike the previously mentioned participants, Heather described a visible physical reaction to receiving her diagnosis when her body seemed to shut down at the knowledge of her diagnosis. Heather responded similarly to the information shared through a leaflet, where she learned about the potential physical distress of going through a form of reconstruction after mastectomy. It is almost as if she could not take such shock and so her body switched off on the spot – a typical 'freeze' reaction to shock (Fink, 2016).

"My initial response was I went into shock and then passed out in the consulting room. […] I passed out whilst I was reading that, 'cos it talked about sawing through your ribcage, and I thought 'eergh'! I thought of saws on top of everything else, and I passed out, and it took me 2 days to manage to read the entire leaflet." (Heather, 54/207)

Throughout all participants' accounts, the distress of their experience of receiving a breast cancer diagnosis was evident. The shared sub-theme of shock was a clear reaction when analysing the accounts individually and collectively. Following that initial shock, participants began to describe the pains (emotional and physical) that were experienced.

2.2 Sub-theme II: 'Pain'

The *'pain'* sub-theme encompasses a wide variety of bodily *(physical)* and mental (*psychological)* pain relating to illness.

Abbi describes the way she embodied the pain of her illness while trying to adapt by making room for it in her body, as she described to me the experience of contorting her body into shapes. It is as if she felt the need to mould her body to the pain she was experiencing. *"The psychosocial and physical burden of cancer pain adversely affects a patient's quality of life"* (Torresan et al., 2015). Abbi's body seemed to be speaking through symptoms (pain and discomfort) while trying to express its needs by articulating a story. Abbi's body gave shape to her sensations and that allowed her to describe what breast cancer treatment had done to her (Frank, 2013).

"In my whole body, it was like a wave and it was…I used to try and lie on the floor and roll around to try and move the pain. It was just absolutely bizarre." (Abbi, 36)

Abbi also talks about her resistance in accepting the role of becoming a patient and being looked after, rather than taking the role of the carer in her family. Taking the caring role as a mother, as a wife and as a provider seemed to come more naturally and be more comfortable, or perhaps is just a more familiar position for her. Additionally, in terms of the relational aspects of men and women in society and more specifically in that regard, perhaps Abbi did not feel safe enough to rely on her partner's skills of being a *"very good nurse"* because he was not conditioned to take that role and assume that position effectively. This could be an illustration of how men and women are taught and encouraged to embody certain gendered characteristics during their formative years.

"I don't, I am not a very good patient and my husband is not a very good nurse." (Abbi, 193)

In the quote below, Fiona describes her decision relating to identity change as she talks to me about reversing roles, going from being doctor to unexpectedly becoming a patient. She asserts that she is a person / woman in her own right and above her professional identity. It seems as though it was important for Fiona to let her patients know that she was in pain and was not going to able to look after them for a long period. Fiona's feelings seem deeply human as she not only accepts her vulnerable feelings and newfound position but also embraces it and shares it with those she cares about. Fiona's experience of illness stands in contrast to Abbi's difficulty in accepting her position of becoming a patient.

"…when I was off sick initially, the practice didn't want to let patients know why I was off sick, and I said 'I don't care, you know I'm going to be off for a while, you might as well let them know', and it was part of my feeling that I'm a person in my own right, rather than just a doctor." (Fiona, 307)

Carol, on the other hand, shares feeling attacked by the news of her breast cancer diagnosis given by her doctor. It seems as though the more she heard about its characteristics, the more she felt her body was being assaulted.

"It was like everything that she said sounded like, every result she gave me, was like I was being punched in the face. [...] She was like 'ok it's invasive', punch, 'it's grade 3', punch, 'it's in your lymph nodes', punch, 'it's lympho-vascular invasion', punch..." (Carol, 92)

Gabi talks about having an intrinsic knowledge based on her experiences of stress in correlation to physical pain. It is interesting that although she feels there's a significant connection between psychological struggles and physical pain, she seems to doubt her self-knowledge about these states. She ends the quote by stating that she could cope with the physical changes of the illness, however, the psychological changes of breast cancer were perhaps trickier to manage.

"*I had some pains in my breast, I was very stressed at the time and I don't know whether this is psychological or not, but I felt that when I was stressed the pains became more increased, and I don't know whether I made that up, but I really did feel it. [...] Very, it was very, emotionally and physically, but the physical thing we can cope with..." (Gabi, 86/94)*

This sub-theme underlines how the physical pain of illness gets closely intertwined with the psychological struggles in relationships with oneself and with others as roles get reversed. Although a lot of pain has already been experienced at that stage, further and more explicit changes are ahead of participants.

2.3 Sub-theme III: 'Body changes'

'Body changes' is an important sub-theme throughout the data and it deals with the final and most explicit stage of becoming the '*Ill Self',* as deep physical changes occur quickly following diagnosis.

After mastectomy, having a reconstruction using her own tissue was not an option for Deanne because she lacked the necessary organic 'material', so she chose not to have a silicon implant either. Despite her breast not being replaced with an implant, Deanne was concerned that the plastic surgeon took care in giving her chest an acceptable appearance and making it look beautiful. This shows her concern about body image aesthetics and how that change would occur in her case.

"I don't want breast, but make it beautiful, make it beautiful, so it looks nice." […] the aesthetic is just [pause] make it…And they did, so I was never in doubt about that, but I had that." (Deanne, 52-54)

In contrast with Deanne, Abbi describes her happiness, as the doctors were able to use her own flesh to reconstruct her breast. That seems to have left her feeling feminine despite the physical pain she endured and the changes in the original appearance of her body. Interestingly, during the interview she misheard my question *"But I wonder if internally, within yourself…"* to which she replied, "*I don't really see it as a new self…*", and then she goes on to add that despite the pain she was reconstructed from her own 'material' and that felt organic. Abbi did not report feeling self-conscious about the changes in her body image, adding *"it is all me!"*

"I was so very fortunate in the type of surgery and then I had probably left me as feminine [pause] and as intact as I could possibly be. You know? Because it was all me and I haven't got a nipple or anything but it really don't bother me. […] I don't really see it as a new self… It was a reconstructed self! […] Traumatic, painful, hard, but it is all me!" (Abbi, 247/283)

Elena's experience stands in great contrast to Abbi's sense of remaining intact after mastectomy. Elena talks about her experiences of how the changes in her physiology were closely related to psychological processes such as the change in perceptions while interacting with her body. She describes feeling detached from the healthy breast after losing the ill breast. In a way she seems to be describing a double loss, even though the healthy breast remained physically intact. Elena's reaction to the stress of physically losing her ill breast and losing touch with her healthy breast could be interpreted as an attack on her sexual wellbeing which is causing her distress. Physical changes after breast cancer were found to produce a range of unwanted feelings (depression, fear, anger, etc.), which have a negative effect on mood. In such circumstances, unwanted feelings are found when the stressor impairs functioning (Dougall & Baum, 2001). The negative meaning attributed to the stressor (breast cancer) by Elena may have given rise to feelings attached to loss of control over her health and subsequently have increased distress in the form of rejection of her healthy breast (Breslau, 2003). Breast symmetry is strongly associated with feminine

ideals of beauty (Eichenbaum & Orbach, 2012) and it seems as though for Elena it was challenging to accept that her breasts were not symmetrical after having a mastectomy and no reconstruction. This unbalance in her breast appearance may have translated into her experience of detachment from the remaining breast, however healthy it may have been.

 "So, I've not only lost the one on the right, but the one on the left was never, I didn't feel, it's funny to say you don't feel quite as attached to it afterwards, but I didn't) […] I think I just I feel a little bit separate from it now." (Elena, 5/11)

Deanne's accounts support Elena's difficult feelings of grief and loss of her breasts (as a pair). Deanne talks about being preoccupied with thoughts of loss during intercourse as soon as her sexual partner touches the healthy breast. Similarly, to Elena, Deanne's concern could be associated with the idealised beauty standards for femininity when faced with the gaze of a sexual partner. Perhaps the worry is connected to being perceived as less feminine and consequently less attractive and this triggers feelings of detachment and grief. Unfortunately, this worry about her changed feminine image seems to keep Deanne's focus away from experiencing pleasure in sexual intimacy. Instead it causes her an unnecessary stress, which according to her is problematic in her sexual relationships. In turn the lack of one breast seems to lead her to a sense of detachment from the healthy breast, as she cannot seem to feel stimulated by touch after having had the mastectomy and no reconstruction. I interpreted Deanne's physical reaction to the stress of losing her breast as a new way of relating to her body, which developed as a consequence of her mastectomy. Her physical reaction of detachment from the healthy breast seems to be an expression of her difficulty in articulating her emotions verbally. This process of somatisation could be a way Deanne's body found to cope with the psychological distress of losing an important portrait of femininity (Breslau, 2003).

"It's very difficult, when someone, they touch my other breast, and then I feel I miss the other one more. I'm not so err, you know, that's the problem really, because I don't want to think about when we have sex either. […] But I find it's not stimulating to touch one because then, in my head, in that moment, I miss the other one [pause] somehow, it sounds a bit strange perhaps." (Deanne, 199-203)

Heather shares her fear and potential sense of loss of control over her body that comes from her research on mastectomy, when she realised that her nipple would also be removed (Breslau, 2003). Heather's account also suggests a feeling of disappointment with the lack of information provided by clinicians about the magnitude of the mastectomy and how such a major change could impact her body image specifically. She then goes on to elaborate on how her breasts and in particular the loss of her nipple could imply a loss of sensitivity, which according to her plays a major role in intimacy. Heather's experience is in line with past research on self-image and sexual changes, which highlights sexual anxiety and changes in intimacy following mastectomy (Marshall & Kiemle, 2005).

"So, she removed the, err breast tissue, I was quite freaked out as it gradually dawned on me doing the reading, that they remove the nipple as well that's not something that you… […] No. If you think about mastectomy when you've not been through the details, and I hadn't been through the details, and it doesn't occur to you, something like that, so your nipple is a whole part of lovemaking, and that sort of sensitive part, and it was like that's going to change things as well [sigh]." (Heather, 219-221)

'Body changes' summarise the experiences of the majority of participants who shared difficult feelings of grief about the physical changes after breast loss – whether reconstruction was an available option or not. Unlike the majority, Abbi was the only participant who reported contentment with her changed body while acknowledging the difficulty of the process. Her account suggests that she feels secure with her sense of *"reconstructed self"* and the emotions surrounding that experience.

This new role – *Ill Self* – was established through the embodied experience of illness and it is the first stage of becoming a breast cancer patient. It is followed by a phase of deep physical and emotional vulnerability.

3. **Major Theme II: *'Vulnerable Self'***

This theme concerns the experience of participants' exposed vulnerability based on *'control'* issues in relationship dynamics, *'uncertainties'* relating to their future and feelings of exposure to the *'other's gaze'.*

3.1 *Sub-theme I: 'Control'*

Broadly, this sub-theme refers to choices or the lack thereof in relation to self and others but also in relation to important events surrounding the experience of breast cancer.

In the extract below, Carol talks about taking control in two different situations related to her body changes. First, she expresses the need to control her hair loss by willingly shaving her head to prevent gradual hair loss as consequence of chemotherapy. Then she talks about the powerful act of choosing to have a mastectomy rather than living with the uncertainty of keeping an untrustworthy breast living in her body. Carol's accounts suggest that she felt strongly that her breast was a potential hazard to the integrity of her body and she just wanted to remove it. As adults, when we fall sick, we are expected to regain control over our bodies and when we fail to do so, even for a short period, all efforts are concentrated in regaining this control as quickly as possible (Frank, 2013). Past studies have found that illnesses limit patients' control over their bodies and over their life's circumstances. Patients described their lives as more valuable through the levels of quality of life gained when in control of their physiology. The empowerment of self is linked to the ability to make important life choices (Rodríguez-Prat, Monforte-Royo, Porta-Sales, Escribano & Balaguer, 2016).

> *"It was nice because I could take control! So yeah, so the hair wasn't falling out, it was [pause] me choosing to have my head shaved, so that was, I knew that I needed to control that, rather than it just happened to me. […] I can't, I just want the surgery. I just want everything out of me, so just cut it out!" (Carol, 157/100)*

By contrast, the quote below illustrates Abbi's apparent relief in surrendering control to the doctor's care with regards to surgery and treatment. Her accounts describe a positive experience of professional care and her trust in the doctor's skills to take care of her during her illness.

> *"If I am honest, you know… They said jump, and I would say how high. […] Whatever the plan was, they were the best placed and that's what I went with…"*
> *(Abbi, 135-137)*

Gabi talks about her reconstruction and making use of a silicone implant as soon as the mastectomy was finished. In a similar vein to Abbi, Gabi described the doctors having made

that decision to have an implant on her behalf and she felt relieved about surrendering control and having one less thing to worry about, so unburdening her of an already complex situation.

"and I was pleased about that because it was as though the decision had been made for me, 'this is how we're going to do it' and it was done, and so I suppose for me it slightly lessened any feelings I would've had about the loss of the breast…" (Gabi, 181)

Different from Gabi, Deanne talks about strong feelings of rejection towards her breast once she perceived it as an enemy in her body. It was as though her cancerous breast had attacked her body and she needed to take control and win that conflict by 'killing the breast' and ridding herself of more potential harm. Frank (2013, p. 30) talks about the struggles of control within the ill body, suggesting *"people define themselves in terms of their body's varying capacity for control".* However, illness brings a loss of predictability and it may be the source of further losses, namely reoccurrence, worries, and more pain, to cite a few relating to breast cancer.

"I'm just, it's just, it's not my friend that breast, I want to get rid of the breast, so then I did. It was terrible. You felt you are living with an enemy on your body. So that was more to get rid of the enemy, so at that moment I just felt really strong, to get rid of it." (Deanne, 18-20)

'Control' speaks volumes about the power struggles of surrendering emotionally and physically to the care of others when feeling unable to tend to oneself. It also refers to taking control of certain situations and interactions as often as possible as a way of regaining/retaining some power over what is happening since the breast cancer diagnosis. The literature of general illnesses frequently highlights the importance of fostering and sustaining a trustworthy bond between patient and healthcare professionals for the reinforcement of treatment adherence (Aldaz, Treharne, Knight, Conner & Perez, 2018). While analysing my patients' reports about managing vulnerable feelings, I noticed that taking control and surrendering control were helpful strategies in maintaining a sense of empowerment over some critical aspects of their ill condition. Taking control, for instance, was perceived as actively directing which way participants wished to take their future,

namely making choices that were suitable and in line with their sense of self. Surrendering control to the care of others, however, was interpreted as liberating for other participants who chose to take a less conflictual approach in navigating through the already turbulent waters of the illness. Both strategies come with drawbacks and advantages. While those who chose to take control felt more empowered in their position as patients it also implies an internal emotional conflict of struggling to accept a vulnerable position. By contrast, surrendering control in my participants' case seemed to take place through a trustful acceptance that a care plan had been designed and implemented to take care of their important needs by qualified professionals who were skilful in the position of carer. However, Rodríguez et al. (2016) found that some patients who described an inability to take care of themselves ended up feeling a loss of self-identity.

3.2 *Sub-theme II: 'Uncertainty'*

'Uncertainty' refers to a range of doubts about self, others and the world. Through this research I have found that illness is strongly associated with the loss of predictability. The loss of predictability seems to have caused participants to feel vulnerable across a variety of life domains and about a variety of important topics strongly tied up with everyday life events previously taken for granted.

Frank (2013) talks about the shared experience of a person's ill body '*for*' each other, calling it *'other-relatedness'*. This concept concerns how the shared condition of inhabiting bodies serves as the foundation for empathic relationships between people. It seems to apply to Abbi's situation, when she describes being faced with her mortality. Abbi shares the realisation that her life could end as result of breast cancer and perhaps life's order would be altered, potentially causing pain to her mother. Sitting with the uncertainty about whether her life is going to end prematurely (before her mother's) seems to have triggered in Abbi a worry about her close family relationships and how much pain her physical departure could cause to the family's structure. Although brief, this account expresses an important thread of the body in pain and the body that causes pain to others as both an individual and collective process. *"She sees others who are pained by her pain"* (Frank, 2013, p. 36).

> *"Yeah, erm, I* think *[pause] I think it made me realise that, [pause] you know, you could die. […] If my mum has to bury me!" (Abbi, 207/315)*

Carol shares a few powerful statements that left me feeling very compassionate towards her with regard to the mistrust she seems to have developed in relation to her body. It was as if her body could attack her any moment given that it has betrayed her before. She also talks about the pain of grief here, when describing how she lost the capacity for pleasure that her breasts once provided her with. It was difficult to hear that a woman could feel so threatened by her own body and organic processes but also that such an important part of her sexuality was taken away, causing a psychological struggle to gain pleasure.

"I don't, just don't trust my body any more... […] I don't know [pause] I just feel like my breasts have let me down. […] One of my breasts tried to kill me softly, so I just, yeah. […] Yeah, so I used to be, yeah definitely, [pause] I felt like I could climax from breast stimulation and now, I just, there's nothing." (Carol, 319-327)

Deanne shares her feeling of vulnerability when she found herself in the position of seeking a romantic partner after the mastectomy. This vulnerability was due to the deep body transformation she experienced, caused her the psychological pain of rejecting a part of herself.

"… thinking about the sexuality and body, suddenly I was much more vulnerable that I should find a new partner. […] I just don't want to focus on the breasts really perhaps." (Deanne, 58/207)

Elena reflects on feelings of loss around missing regular professional care after ending the five-year follow up. She described that even though there was apparently nothing "non-functioning" in her case, she was still willing to engage in having her fears explored in a clinical setting by healthcare professionals.

"Not, I wasn't non-functioning, I just, I just felt a bit bereft, kind of 'don't abandon me, I'm not ready yet', you might be, you might think I'm fine (laughs) but I'm not ready yet." (Elena, 167)

Fiona asserts her position as a patient when talking about also being vulnerable to illness despite being a doctor and having *"the skills"*.

"They know I've had breast cancer, which I was quite happy to tell people, because I think as a doctor you need to show people that you're just a normal person as well. Erm, you know, you're nothing special really, yes you have the skills, but, you know, you can still get all the normal illnesses that anybody else has…" (Fiona, 249-251)

'Uncertainty' summarises broad feelings of vulnerability in the face of changes brought on by the illness. Amongst the vulnerable feelings of the participants were the contemplation of their own mortality, the vulnerability of their bodies to reoccurrence, a loss of trust in their bodies, anxieties around seeking a new romantic partner during recovery, and missing regular professional care. The vulnerable feeling of uncertainty led to self-doubt and fears about how participants might be perceived by others.

3.3 *Sub-theme III: 'Other's gaze'*

This sub-theme refers to my participants' experiences of self-concept as they question their concepts of femininity and sexuality relating to body exposure to other's judgement.

In the quote below, Abbi speaks about her fears and difficulties in managing her self-concept in relation to her partner. She believes that he finds her unfeminine because of her bald appearance. Abbi adds that although she does not seem worried about her looks after the cancer treatment and mastectomy, she is concerned that her partner is withholding his gaze because it is hard for him to face her body changes. Abbi frequently makes use of this phrase, "*If I am honest, you know".* It makes me feel as though she is seeking reassurance from me. The interaction with her partner described above seems to have left her feeling somewhat insecure about her looks because her breast was reconstructed but it still bared scars and lacked the nipple.

"And, I think Mark, my husband, sees the same thing. He looks at me and he sees my dad!" […] Because of the way I look. […] But it can't be, I think, it can't be nice. He looks at me sometimes and sees my dad… […] A scar on my breast but it didn't bother me at all, but I could tell something's [pause] that he would sort of look away and things like that… […] I just said you know, [coughing] you are going to have to look at me at some point." (Abbi, 68 / 76 / 119)

Barbara is also describing the other's gaze and how she felt the need to adapt the way she dresses as a way of concealing the mastectomy due to the loss of her cleavage. It seems indicative that although she was happy to have had the surgery, there are still lingering concerns about how her physicality is perceived by others.

> *"They've advised me that I had a mastectomy and I was absolutely happy with that decision. They asked me if I wanted reconstructive surgery and I said no and I have been completely happy with that too except that there was that little crease that I hadn't realized that I was going have to wear really quite high cut things." (Barbara, 155)*

Deanne also shares a lack of satisfaction with her body image in interpersonal relationships. She was faced with being a single woman with a single breast and wondering whether she would be perceived as sexy after that body change, which shows her concern about men's gaze. The comparison with women who have two breasts shows her disappointment about the loss of her breast. I can sense a feeling of inadequacy from having only one breast in comparison with someone who is not physically scarred or who has had any bodily modifications. Arroyo and Lopez (2011) argued that the loss of a breast leads patients to experience a poor sense of self-worth and a changed sense of femininity. That decline in self-worth was found to be directly linked to the loss of a body part that is highly valued by women and men as an important erotic object in interpersonal intimacy. Having the breast removed as a result of mastectomy can impact directly on woman's perceptions of being sexually desirable to their partners.

> *"And with my partner who left me for this younger woman is [pause] I realise that I often think of, I'm not jealous with her, and when he was like that it's not man, I really want, and so on, but I often think that she has two breasts…" (Deanne, 78)*

Unlike Barbara, Carol talks about her feelings of sadness for not being eligible for a breast reconstruction. Her husband fears for her health and pleads for her not to go ahead with it. Carol's ineligibility was due to the length of the surgery and how that might have had a negative impact on her other existing health conditions. That lack of choice in having a reconstruction brought up in Carol feelings of inadequacy and deep sadness. According to Marshall and Kiemle (2005), reconstructive surgery was seen as an option to improve

women's self-image as the symmetry (equal breasts) was found to give women a sense of appearing normal to partners and consequently within themselves,

"… and my husbands beside me now at this point and he's like 'no I don't want you to have it. I don't want you to have this'. […] Because of the risks. And so that was really upsetting…" (Carol, 22-24)

Likewise, Elena talks about her need to look physically acceptable to her partner. She also shares an apparent need to look at and to show her scars, perhaps a way of being validated as a woman and as a romantic partner.

"I felt, I felt very strongly, that I needed to look at it as soon as I could, and that my other half had to look at it, 'cos that would've been terrible if he hadn't been able to." (Elena, 313)

Heather also shares Elena's fears about potential changes in her relationship with her partner. Heather was worried about being accepted not only as a suitable partner but also as an attractive sexual woman after the loss of her breast. That statement reinforces women's concerns regarding the other's gaze. She reflects on whether her new body image is good enough following deep physical changes and the loss of a body part that although secondary, is very important in sexual relationships.

"I wondered whether my husband was going to find me attractive, we'd been married for just over a year then." (Heather, 78)

As a major theme, the *'Vulnerable Self'* encompasses feelings of embodied exposure (physically and emotionally) to the scrutiny of others. That exposure had the potential for either rejection or acceptance from others as participants were faced with deep and unwanted changes in their feminine appearance and sense of self. Participants' journeys through this second phase where they had their raw vulnerabilities exposed triggered their need to find a suitable way of expressing and coping with the difficulty of the feelings they were left with.

4. **Major Theme III:** *'Coping Self'*

The *'coping self'* expresses the resources my participants used to recover from illness and regain wellbeing while going through losses.

4.1 Sub-theme I: 'Warrior'

The '*warrior'* sub-theme talks about my participants' survival mode – the experience of psychological robustness in the face of a potentially life-threatening disease.

Abbi is candidly offering me insight into her resistance to being in a vulnerable position and how although she can feel the vulnerability of being unwell, she is fighting that role. It suggests that she sees vulnerability as a sign of weakness to be overcome rather than an intrinsic part of her experience.

> *"But this second time it made me feel definitely more vulnerable and that is not something that I do. I don't do vulnerable and I don't do stuff like that…" (Abbi, 209)*

Carol's account suggests that she knows that although she's trying to maintain a façade of wellness, she can feel that it is in fact a superficial *"veneer of coping"* because she's still vulnerable and not yet feeling fully recovered.

> *"Yeah, like I'm not quite coping, underneath. I have this veneer of coping." (Carol, 467)*

Similarly to Carol, Deanne is talking about the creation of façade of coping, the Greek warrior embodiment as a way to preserve her psychological and physical integrity. She seems to be shielding herself from the psychological pain of her experience while fighting through her illness with dignity. Deanne's responses to my improvised question: *"What was it like for you sexually to feel like your breast was your enemy?"* was the description of her way of coping. This was in the context of her emotional resources being low following the sudden death if her partner during her recovery. Although Deanne did not seem to have that important external emotional support resource from her husband any longer, she showed a sense of resourcefulness contained within her, which seemed vital in her recovery process and which is illustrated by her powerful metaphor of embodying the amazon persona.

"I was just an amazon, you know an amazon is a Greek warrior. […] Yes, it was my way to survive. […] Be straight back, and strong […] "But it's good to say to protect yourself, 'I'm an amazon', and then they don't get it underneath, and then you say 'but I told you I'm an Amazon', and then I can tell the story about the amazon, so I use the amazon as a strong woman, you know." (Deanne, 24/32/34/157)

Elena's experience of pushing through a very painful situation while taking care of the wellbeing of her family seems to have brought up the realisation of being the main pillar holding the family together, and therefore this meant that she "*can't afford to fall apart.*" Elena seems to hold the belief that if she *"falls apart"* maybe the whole family system would collapse. Falling apart seems to mean allowing vulnerability to be embodied and embraced as part of the process of recovery from illness. For Elena, however, she seems to see it as a weakness to be overcome.

"And the overwhelming part of your brain just is in survival mode, you just want to get through this, you want to be alright, more than anything else you need your children to be alright, you want your partner to be alright erm, so you are not, you realise you are in a very busy system so part of you, you can't afford to fall apart." (Elena, 215)

Elena talks about her partner sharing his fear relating to her illness and how she felt as if she could not hold him through it. Elena suggests that her partner needs to *"take that somewhere else"* because at that point in time she cannot be doing most of the *"emotional work",* as is expected from her role as a woman, mother and wife. I interpreted that as Elena's needs for self-care and embodiment of her vulnerable feelings. She needed her partner to contain his emotions because on that occasion, when her life was at risk, she could not take that role of being the one who caters for the family's overall needs. Rather, the roles had reversed, and she needed the family to look after themselves, so she could use all her emotional resources to recover from illness. Perhaps that was her way of rebalancing care – Elena seems to have identified that her husband's helpless attitudes towards her illness could jeopardise her psychological integrity. Her account can be interpreted as an attempt to assert herself as someone who not only has needs but also is allowed to express those. That attitude breaks the social construct, which places women in

the position of overlooking and denying their needs, showing selflessness for the wellbeing of others (Eichenbaum & Orbach, 2012).

"… 'if you die, I'm gonna be really angry', he said 'I can't face that' [crying] […] I used to say 'you can't say that to me, you have to, what you have to do is tell me that you'll be alright, and the children will be alright. […] If you feel angry erm, you're to go and take that somewhere else, but don't, I've got enough on my plate at the moment'… […] … women already sort of do 99% of the emotional work in a family I think." (Elena, 225)

Elena shares her sense of feeling under pressure to cater for everyone else – as a mother and a wife – and how she viewed her position as a breast cancer patient as being no different from the time when she was healthy. She seems to be experiencing the weight of her obligations in sparing her family from suffering even though her emotional resources are low. Eichenbaum and Orbach (2012), argue that women's social role in society is based on nurturing others above their own needs. That can be detrimental to women's wellbeing as the emotional catering for others' feelings is often unbalanced and not reciprocal. In the extract below, I interpret Elena as sharing her social learning about the emotional deprivation that is expected from women when faced with challenging situations.

"Yeah, but you also feel under a huge obligation to make everything alright for everybody. […] Absolutely! Yeah it had to be business as usual [giggles] as far as I saw." (Elena, 237)

Fiona shared her preferences about attending medical appointments alone because then she could then talk in such way that would ward off the difficulty of her feelings. She identified that as a coping strategy to get her through without having to use her emotional resources to cater for anybody else's feelings for a while. It indicates a self-preservation mechanism that carried her through the difficulty of making sense of her illness while applying it to her context, rather than that of a patient. Similarly to Elena's experience, Fiona felt that rejecting her partner's presence in the consulting room while discussing her illness would be more beneficial as she would not have to tend to his feelings. Had her partner been in the room she would have felt the obligation to fit the expected social role of *"looking after him"* and that would go against the feminine role of socialisation (Eichenbaum & Orbach, 2012).

"I went by myself to all the appointments because I just felt that that way I could talk to them medically, and yes, it would be me that would be involved, but it sort of helped a bit that I could talk purely medical with them. […] And I suppose in a way that sort of took it one step away from the emotions. […] … I would be looking after him [partner] more than me and I couldn't cope with that." (Fiona, 106/110/113)

In support of Fiona's accounts, Heather also described her need to *"hide in an intellectual place"* so she could cope with the difficulty of the situation without getting over-involved with vulnerable emotions. Anllo (2000) argues that a state of denial during the early stages of diagnosis can be beneficial as a coping strategy, since it helps women to maintain some level of emotional wellbeing given the difficulty in managing the experience of loss of physical integrity.

"Then I was waiting to see what the results were, and they told me it was cancerous, and the thing to do was have a mastectomy, and at that point I flipped into kind of rational mode… […] I didn't know what to, I didn't know how I really felt about myself, and I wanted to kind of trying to hide in an intellectual place, keep it at arm's length for a bit." (Heather, 131/259)

The *'warrior'* expresses participants' reactions to a range of vulnerable emotions such as anger, hopelessness, anxiety and sadness. It shows how participants resisted accepting a vulnerable position in relation to illness by creating a 'strong' façade and/or seeking a less emotional and consequently more intellectual space. That coping strategy seems to have been developed as a way to spare their loved ones from pain while they managed their difficulties rationally rather than "*falling apart*" or being perceived as weak.

4.2 Sub-theme II: 'Comparing losses'

'Comparing losses' is a sub-theme that illustrates how participants made sense of moving forward while taking stock of what had happened to them during illness.

Abbi compares what she has to cope with having breast cancer to her colleague's mundane issues. Abbi expresses her anger towards those who complain about mundane problems, which are not life threatening. She compares her loss to that of others who had different losses or hardships, while trying to weigh up which is more painful and more complicated to

manage. However, she quickly goes into a deeply empathic place and self-regulates by considering that others' losses are not greater or less significant than hers. That self-regulation seems to not only keep Abbi considerate of others' suffering but also helps her begin to acknowledge that getting through breast cancer has been a heavy burden to carry and at times too much to hold when compared with some less critical life issues.

"[Tearful] Especially like I said, the work I have done, the amount of people I was responsible for when you hear sometimes some of their angst and problems. I am listening, but then at the same time I am thinking and excuse my language, 'you haven't got a fucking clue'! 'You haven't got a clue!' And, but equally I have to give myself a shake and go, but that is the worst that they experienced in that moment and that is their worst! […] So, I have to be quite mindful that I am not being too erm, harsh. [Tearful]" (Abbi, 317)

Barbara shares her experience of talking about her illness in the research interview. Sharing her feelings and perceptions of her breast cancer is something that she did in the company of very few and selected people during the whole process from illness to wellness. She seems to be making sense of why it might be helpful to talk by acknowledging the value of professional help – even though my role is that of a researcher in this occasion. Barbara's accounts of the importance of sharing her story in a contained and safe environment are in line with past research findings that have identified the offer of psychological support in this journey from illness to recovery as valuable (Fobair et al., 2006).

"Maybe because I don't talk to people all the time it feels almost therapeutic to talk about it. I don't have to go away from here feeling that I have told you too much…" (Barbara, 413)

In retrospect, Heather discusses how exploring the experience of mastectomy with her partner helped them make sense of it as a couple. Previous to that extract, Heather was talking about her *"frustration with some of the processes at the hospital"* and her struggles in weighing her options as to whether to have a reconstruction, because she felt confused about *"how to make a rational decision there, so anyway it's partially an emotional decision as well".* Her account suggests that it was helpful to share her concerns with her husband as a way of managing the changes ahead. Heather had brief couple's therapy after the

mastectomy and shared that she would have benefitted from more sessions if they had been available. Male, Fergus and Cullen (2015) found that breast cancer patients mainly wrestle with sexual functioning issues and distortions in body image, however, relational issues are also an important factor influencing patients' wellbeing after mastectomy and the provision of a specialised service is not widely available.

> *"I started thinking about how I'd feel about not having a breast on one side, started then being able to, it then gave me time to think about what my options were at that point, did I want to try and have some form of reconstruction or not? And I think actually having the time and space was useful to talk it through, my husband has a tendency to always do that, well maybe, or whatever you think, which is really supportive but not sure what was going through his head. […] When we were doing a compare and contrast on how that makes you feel, and that in some ways it was quite useful, it was quite useful for Ian, my husband to be involved in that…"*
> *(Heather, 137)*

'Comparing losses' was an important part of coping, as it seems to have been the place where repair began. Participants compared what was lost during the crisis and what could be repaired moving forward. They reflected on the extent to which their roles had shifted since the breast cancer diagnosis and also on their experiences of sharing with others and the importance of specialised care to help the recovery phase that followed.

4.3 Sub-theme III: 'Recovering'

'Recovering' is about the systems (support) that my participants had available to help them get through illness to regain wellbeing and improve their quality of life after mastectomy.

Carol describes the benefits of being part of a network of support – in this case social media support groups – as the means for exploring some common shared struggles during and after breast cancer. However, she also points out her concerns about the content of the emotional and personal material being shared online. She talks about keeping sensitive content away from online platforms and that made me feel as though she was protecting her boundaries by keeping her *"psychosexual stuff"* private and offline. Her accounts raised my concerns about the importance of offering a boundaried space to those willing to discuss

their experiences of sexual changes after illness in the safety of the therapy room and in a more personalised, intimate and confidential setting.

> *"Yeah, it's a closed Facebook group, but maybe I don't discuss the sort of psychosexual aspects there, maybe it's sometimes it's just general stuff like, life, side effects, that kind of stuff. […] Yeah, the conversations do happen sometimes, but the conversations are wide ranging, so that's only part of it. […] I probably wouldn't say too much online, just 'cos, you know, you never quite know, and they are very much sort of, the moderators would say 'we are here for support but be careful what you share online'" (Carol, 345/347/349)*

Indirectly perhaps, but in support of Carol's accounts, Heather shares her doubts about how to make sense of such a life-changing experience when she feels that she does not have the vocabulary to do it. It seems as though Heather could benefit from specialised services that complement her existing network of support. Heather's account reminded me of the importance of improving access to specialised clinical discussions about psychological support. Past research shows that patients recovering from breast cancer have shared their issues in addressing sexual concerns and building a narrative of experienced events as a way of improving quality of life (Reese, Porter, Bober, & Lapore, 2017).

> *"So, it was useful trying to just talk around it, and go but we haven't got the right words for this, how do you describe your feelings?" (Heather, 151)*

Similarly, Fiona conveys a search for a suitable space where she can express her emotions as a way of validating her experience while unburdening her concerns safely.

> *"So, it was just, and as much as anything, it's expressing it really, erm and realising what you're feeling, that is an important thing about that, there was probably nothing they could do, but it's just nice to have got it off your chest, in a way." (Fiona, 305)*

Deanne refers to her experience of refocusing in on herself after consulting with her body and addressing the need for a shifting perspective about recovery. She expresses her doubts about how to move forward by trying to make sense of her experiences of loss. That

gave rise to the exploration of ways in which she could cope with her feelings of grief as a way to regain balance – in other words, to recover wellbeing.

> *"… I did a big check up with my body, and said, 'ok one thing at a time, that was him and now it's me.' […] How do we cope? How do we find balance? And that's what I've always struggled or worked with anyway, and this meant like knock down a few times, and then you try to find balance again…" (Deanne, 135/265)*

Heather outlines how couple's therapy was helpful in offering her and her partner the space to consider other ways of relating that did not necessarily involve sexual intercourse. That seems to have broadened her horizons about a whole spectrum of intimacy not previously considered in the context of her body changes. Heather's account stands in contrast with those of some of the other participants who spoke of a distance being created between them and their partners, which added to the feelings of separation from the healthy breast following surgery. Heather's account suggests that she was better prepared to recover from potential sexual difficulties with the help of psychological therapy. While exploring women's concerns about sexuality after breast cancer, Fobair and Spiegel (2009) found that relational issues regarding attachment might occur in couples experiencing sexual problems, as feelings of distancing between partners are not uncommon following treatment. However, sexual and relational difficulties can be predicted and discussed through an open communication between patient and clinician. In addition, the use of couple's psychotherapy and the promotion of a more securely attached style can be encouraged in dealing with the relational emotional challenges.

> *"Just re-emphasising the idea that it's ok, you don't actually feel like full on sex, the intimacy of just touching or holding hands or cuddling together, is part of a spectrum of stuff. […] And that's good. And if you are feeling like 'don't touch me', 'cos you are in pain, you could do a foot massage or something else instead, there are other ways to express physical comfort." (Heather, 233-235)*

'Recovery' highlights explicitly my participants' concerns about having an open and safe environment in which to express their emotions regarding their altered sense of femininity and sexuality. This final phase of the 'Coping Self' seems to be about refocusing, regaining balance, improving the quality of relationships and recalibrating life's priorities as

participants move into wellness again. These women seem to have come through a long and dark tunnel in their journey from wellness to illness and then back again to share their narrative of recovery.

> *"It's just, it just happens, the only way I can describe it it's like going through a tunnel, you're here and you have to get to the end, you don't quite know what the end is, but you have to go to the end." (Elena, 249)*

5. CHAPTER FIVE. DISCUSSION

"I think anything which gets people to talk about it and also allows women to feel that they can discuss stuff is really helpful."
(Gabi, 467)

Overview of the Chapter

In this final chapter I discuss the findings of my Interpretative Phenomenological Analysis in relation to my research question – *how breast cancer patients experience (physically & emotionally) their femininity and sexuality during the rehabilitation phase of mastectomy.* Initially, I present a brief summary of the key findings that emerged through my data analysis. Subsequently, I situate my findings within a broader frame of research. The master themes found were the '*Ill Self*', '*Vulnerable Self*' and '*Coping Self*'. Then, I suggest some future directions focus, and identified gaps for further research, while also exploring the strengths and limitations of the present study. I reflect on the methodology I used and my embodied/reflexive experiences of undertaking the research. Following that, I discuss the practical implications of the results for specialised psychological services and for the wider context relating to other healthcare professionals. I end this chapter with a brief summary and conclusion of my study.

1. Key Findings of the Present Research

Broadly, the key contributions of the present research involve the comprehensive account of participants' embodied struggles with changes in identity (healthy-ill) brought by the onset of breast cancer (mastectomy), at diagnosis and throughout recovery. More specifically, the findings of the present research discuss participants reports of their perceptions, feelings and reactions connected to changes in identity, sexual intimacy struggles and ways of coping after mastectomy.

Changes in identity refer to participant's perceptions of shifting their original position of healthy, fully functioning women to becoming breast cancer patients. Such shift in identity was perceived as a role reversal (from carers to being cared for) and as a loss of health, causing a deterioration of wellbeing. After the initial breast cancer diagnosis and consequently the mastectomy, intimacy issues became apparent. In the present study, sexual intimacy issues are defined by any close relationship to oneself and/or to others.

Within the findings linked to intimacy struggles were the physical changes experienced, which also resulted in feelings of self-doubt and loss linked to appearance changes after mastectomy. Self-doubt consequently led to women's struggles with sexual intimacy with partners and to disconnection from their bodies (e.g. loss of sensitivity through loss of nipple).

Amongst the findings relating to ways of coping, a few different strategies were employed. As a way of adapting to hardship, some participants chose to attribute meaning to the experience of illness rather than invalidating it, whereas others resorted to an initial rejection of vulnerable feelings as their perceived it as a weakness to be overlooked. Some women chose to make changes in dressing (e.g. avoiding certain clothing) to suit their body image after breast removal, while others made change to their body image (e.g. implant) to suit the acceptable standards of female aesthetics (two even breasts). Participants also found that talking openly with important people in their lives (e.g. partners, therapists, work affiliations, etc) was a helpful way of processing their difficult experiences. Thus, women reported that drawing comparisons between their experience and other's experiences of illness was a helpful way of coping. Findings also yielded that, help-seeking behaviour fosters encouragement to improve communication of struggles between patient's and the relevant people in their lives, fostering intimacy and consequently the development of adaptive adjustment to the experience and the recovery of wellness. Recovery of wellness means, regaining balance by returning to or redesigning a fully functioning healthy identity through the acceptance of hardship and with social support.

The detailed findings of the present research can be found in the section below, where I explore and discuss my findings within the backdrop of a broader frame of research.

2. **Situating Findings within a Broader Frame of Research**

2.1. Major Theme I – 'Ill Self'
The '*Ill Self*' major theme conveys participants' feelings, beliefs and responses to a range of physical and psychological experiences in the context of illness. All participants expressed the difficulties faced in this first stage of diagnosis and how that seemed to have shifted their position from being healthy to becoming a patient. Evidence suggests that a change in identity through the experience of breast cancer diagnosis, followed by an altered self-

image, can trigger a variety of psychological processes and consequently a decline in wellbeing status (Hungr, Sanchez-Varela, & Bober, 2017). That decline in wellbeing may be understood as the symbolic loss of health through illness, a type of grief that has been fairly recently recognised by grief theorists (Pillai-Friedman & Ashline, 2014; Boss, 2009). This model of grief taking a more symbolic psychosocial stance is in great contrast with more linear past models of grief as presented by Kübler-Ross and Kessler (2005), where the ultimate goal lies in the feelings of closure and acceptance of loss coming full-circle. Also relevant in this major theme are my participants' views on interactions with their bodies and how these are expressed through self-image as they lose/gain body parts (mastectomy and reconstruction). Participants regarded the changes brought by illness as threatening to intimacy.

The psychological responses to breast cancer have been described as a constant chain of feelings that vary according to the stages of illness (Breslau, 2003). Evident in the present analysis was the *shock* participants experienced upon receiving the diagnosis of breast cancer. All participants without exception reported feeling immediately surprised and fearful. Abbi, for instance, described her immense surprise in first receiving her diagnosis and later learning the gravity of her tumour *"which is a quite difficult one to get on the top of"*. Similarly to Abbi, Fiona described finding the lump thorough self-touch. Being a doctor, Fiona was immediately convinced that it was a cancerous lump. However, after the test results she was shocked to learn how fast the illness had already spread and that she would have to undergo mastectomy. My participants' reactions to the diagnosis are congruent with the strong emotional reactions found in female patients experiencing loss of healthy identity (Keitel & Kopala, 2000).

The initial shock of diagnosis led to a variety of reactions across the participants. In Barbara's case, for instance, I offer a phenomenological 'empathic interpretation' of her reaction, which acknowledges her attempt to make sense of how she became ill in the first place through an apparent self-blame. *"'Empathic' interpretations are motivated by a desire to get as close to the meaning of a text as possible by trying to understand it 'from within'"* (Willig, 2017). Heather, on the other hand, displayed visible shock at her diagnosis, describing that she *"passed out in the consulting room"*. That embodiment of shock was experienced once again as she was researching about a particular technique of breast reconstruction after mastectomy, which involved very intrusive methods. Heather's

experience of shock was a typical freeze response (Fink & Elsevier Freedom Collection, 2016) and that reaction seems to have helped her to slow down treatment procedures by six months while she considered whether she was willing to undergo mastectomy and then reconstruction. Deanne experienced the diagnosis differently from the others. Although cancer was a reoccurrence for her and she already had a child from a previous marriage, Deanne was concerned about her social role as a wife and mother. Deanne's concerns are in line with the results of an extensive literature review carried out on younger women (up to 45 years old) diagnosed with breast cancer. Adams et al. (2011) reported that younger women are often faced with age-specific challenges relating to childbearing. Based on an extensive literature review, Adams et al. (2011) concluded that such challenges are closely connected with developmental perceptions of normalcy within womanhood: younger women perceive that normal femininity and sexuality are not achievable unless they are able to reproduce.

Despite the uniqueness in participants' reactions to diagnosis, I noticed an intense experience of distress shared across all cases as their wellbeing was suddenly at risk, causing mostly fear and anxiety. At the receipt of diagnosis, a new and sudden role began to emerge beyond participants' control. While exploring that sense of role change – losing the healthy identity – participants went through the exploration of *'pain'* and how physical hurt seemed intrinsically intertwined with psychological struggles. The exploration of my participants' connections between physical and psychological pain is an important part of this major theme, as disambiguating one from another proved a challenge, supporting embodiment theories that mind and body are interwoven (Carel, 2012).

Abbi's accounts communicate clearly her struggles in adapting her body to the cancer while experiencing the aches and pains of her chemotherapy. She discussed the struggles in moulding her body to illness, sharing how that affected her quality of life through her accounts of contorting herself on the floor to try and shift the hurt she experienced internally. At that point, I remember Abbi making the embodied gesture of wriggling her body in such way, as though she was trying to show me the discomfort she experienced more explicitly. I was attuned to how she described her body as giving shape to the waves of pain she was experienced. Similar accounts of such lived experience of illness can be found in past literature. Frank's (2013) account, for example, argues that bodies need voices, discussing the body's inability to articulate in words the phenomenon of illness. That apparent lack of

verbal eloquence is replaced by the expression of body language, creating an embodied narrative.

In addition to Abbi's physical pain, she also expresses the psychological struggles in settling into the role of a patient, discussing her resistance to accept that she is the one who needs looking after rather than being the one in the carer role for her family (Eichenbaum & Orbach, 2012). Hearing about my participants experiencing such painful processes simultaneously, both inwards (relationship within self) and outwards (relationships to others), I identified their struggles in separating physical pain from the psychological. That is a struggle I shared while analysing the data and perceiving these processes as being intrinsically intertwined.

Fiona explored her sense of role reversal (doctor-patient) by describing the importance of not only accepting that she was becoming a patient but also realising that her identity as a person/woman was greater than her professional identity as a doctor, and embracing this (Oris et al., 2018). She discussed how she went against her practice's suggestion of keeping her diagnosis hidden from her patients. For Fiona, the changes in her professional relationships needed to be addressed openly because she knew she was going to be away from work for a while. This attitude demonstrates Fiona's role assertion and relational concern as she described later in the transcript, *"I felt that many of my patients I knew very well, because I've worked in the practice for 25 years, I think they had a right to know."* (Fiona, 309). Fiona's experience of her body seems to have a significant connection with a social role change and with her self-esteem (Oris et al., 2018).

The occurrence of an unpleasant event in itself is not sufficient to cause stress but rather whether a stressor is perceived or interpreted by the individual as intimidating or wounding (Dougall & Baum, 2011). Carol described having received the diagnosis as if she had been emotionally assaulted by the illness. In this situation, she interpreted the receipt of her diagnosis as an extremely stressful situation, which seemed threatening to her healthy status (Dougall & Baum, 2011). Also relevant was Gabi's account that, similarly to Carol, she had also experienced the psychological aspects of diagnosis as harder to manage than the physical struggles, suggesting that she experienced somatisation of her psychological distress. Breslau (2003) clarifies the link between *"psychological stress, the stress response of distress, and the preoccupation with one's body"* in women with breast cancer. Breslau (2003) proposes that when the body is invaded by chronic illness (cancer), physical

symptoms can be found in reaction to experienced psychological stress. Gabi could have ruled out her breast pain as a physical manifestation by consulting her doctor, but instead she seems to have come to a self-understanding that although it seemed odd at first, the connection between the physical pain and psychological stress was clear - "*I don't know whether I made that up, but I really did feel it.*" *(Gabi, 86)*

While attending to my participants' experiences of changes in their self-image through the physical alterations endured, I also observed that this new emerging role – '*Ill Self*' – was gendered across all participants. That observation was present in my participants' accounts about the magnitude and quality of changes in physical appearance, which was found to be intrinsically related to their sense of femininity but also closely linked to their role as a woman in society (Eichenbaum & Orbach, 2012).

Deanne shared her worries about the aesthetic changes after the breast loss. She said that although she was not willing to have an implant it was important to make sure her chest was visually acceptable, showing a level of body image dissatisfaction. Other participants made similar comments. A notable outlier here was Abbi, who described body satisfaction after mastectomy, expressing her self-perception of a *"reconstructed self"* rather than a *"new self"*. Although Abbi shared concerns in relation to her partner later in the *'Vulnerable Self'* position, her accounts of the *'Ill Self'* about self-image, stand in great contrast to the other accounts. Abbi was able to keep her sense of femininity intact after the surgery despite the stress of the overall experience. Past literature on reconstruction suggests that patients who have immediate breast reconstruction report higher levels of satisfaction and increased wellbeing (Al-Ghazal, Sully, Fallowfield, & Blamey, 2000). Abbi's reports can illuminate the value of having options with regard to mastectomy and breast reconstruction. Her body satisfaction seems to stem from having the ability not only to endure immediate reconstruction but also to use her tissue (DIEP) for this, which unfortunately is not an option for all women.

Also relevant were Elena's accounts about feeling separated from the healthy breast after the changes brought by the surgery. Dougall and Baum (2001) maintain that bodily changes after mastectomy often lead to difficult feelings and in some instances cause impairment in functioning. In Elena's case I identified feelings of loss not only of the mastectomised breast but also of the remaining healthy breast, as she felt disconnected from it after surgery. This

can be understood in the context of past literature examining the connections between psychological stress and stress response in relation to the body. Breslau (2003) provides a frame for understanding the connection between physical distress (mastectomy) and psychological strategies. When experiencing high levels of stress, Breslau (2003) suggests that breast cancer patients tend to develop coping strategies in order to adapt to the stressor (breast cancer). However, if there is a failure in adaptation or if the strategies implemented do not protect the individual from psychological distress then a series of physical symptoms (somatisation) may be developed instead (Breslau, 2003). For Deanne, in addition to the somatisation illustrated by the loss of sensitivity in the healthy breast, I found feelings of loss in the context of her femininity. Though secondary, the breast is portrayed as a feminine sexual organ (Almeida, Guerra & Figueiras, 2012).

Through Heather's extracts it is also possible to identify concerns about body image in connection to the sexual changes that the loss of her nipple could bring. This is particularly relevant for Heather's sense of femininity and intimacy in lovemaking. Heather's experiences can be compared to Marshall and Kiemle's (2005) findings regarding the significant links between breast reconstruction and the maintenance of self-image for women. Heather's experience, however, also goes beyond the self-image as she engages with difficult feelings about the embodiment of mastectomy/reconstruction and the loss of sensitivity during intercourse (Carel, 2012). Lastly, at this initial stage, Heather's account hints at the lack of exploration healthcare professionals made about potential body image and sexual changes after surgery; she expresses feeling *"freaked out"* as she came to the realisation of the loss of her nipple, indicating the fear she experienced. (Henson, 2002)

Participants shared their embodied experiences of femininity and sexuality through the exploration of how meaning was obtained out of that unexpected emerging identity, by addressing new functions to their bodies: once carers, now being cared for. They went from leading fully functioning and fulfilling lives to becoming cancer patients who partially and temporarily lost their healthy identity and autonomy. Although the shift experienced was fast and unplanned, participants also seemed to have experienced it as an organic progression from being healthy to falling ill in the initial stages of diagnosis and treatment. Such experiences led to the development of a new role – *'Ill Self'* – as participants learned about breast cancer diagnosis and its physical and psychological implications. This initial stage preceded a state of embodied exposure of vulnerabilities.

2.2. Major Theme II – 'Vulnerable Self'

The *'Vulnerable Self'* is the second major theme and it was identified through participants' exposed vulnerability in relational dynamics but also vulnerability to the challenges presented by illness. Within this second theme, I discovered participants' power conflicts with others (doctors, carers, partners, etc.), exemplifying their struggles in surrendering and taking power. Due to fear and anxiety, some participants kept a tight grip on having as many choices as possible and fought for power over the processes involved in the treatment of breast cancer. The *'Vulnerable Self'* theme also illustrates women's concerns about the *uncertainties* that lie ahead in recovery and the feelings of exposure to the *other's gaze* during the recovery process*.*

While contemplating the potential hair loss that often follows chemotherapy, Carol expresses her need to take charge by making the choice of shaving her hair to avoid the hair loss happening to her. Carol also felt strongly about removing the ill breast as a way of ensuring that it would not be a potential threat again in the future. Carol's responses can be linked to a review of past qualitative research on patients' perspectives of dignity, autonomy and control at the end of life. Rodríguez-Prat, Monforte-Royo, Porta-Sales, Escribano, and Balaguer's (2016) findings point to a patient's need to keep functionality, control and autonomy in chronic illnesses as a way of preserving dignity. Deanne shares similar concerns about preserving the integrity of her body as she finds that taking control over her body is also a way of preventing further psychological struggles such as fear of recurrence and of further losses. These findings convey the importance of keeping control over one's body as a way of regaining some predictability (Frank, 2013). Additional research shows that the capacity to make important life choices such as having a mastectomy is strongly connected to a sense of self-empowerment. This is perhaps illustrated by Deanne's and Carol's need to seek their own directions as a way of keeping some level of autonomy over their experiences (Rodríguez-Prat et al., 2016).

By contrast, despite the initial shock of diagnosis, Abbi described having quickly made the conscious choice of releasing the grip of control relating to the mastectomy and reconstruction. Abbi was glad to follow the doctors' suggestions and trusted they knew what was best for her. Aldaz, Treharne, Knight, Conner and Perez (2018) defend patients' attitudes in depositing trust in the medical staff as a helpful step in ensuring treatment adherence. Throughout Gabi's account I also found a clear sense of relaxation as she

surrendered control to the doctor's care. Abbi's and Gabi's extracts stand in contrast with Rodríguez-Prat et al.'s (2016) findings, where it is suggested that a sense of disempowerment is developed and in some cases loss of identity is found when patients perceived having no control over processes relating to their health. In the present research, surrendering control was found to have released Abbi and Gabi from the heavy burden of choice-making. As they surrendered control, they metaphorically released the grip of the power handlebar and enjoyed the safety of riding this new role of becoming patients and being looked after – an unfamiliar position for most.

Participants shared how vulnerable feelings were closely related to finding themselves sitting with a range of *uncertainties* that followed several changes in their internal and external world, including relationships. They demonstrated various doubts about self, about others, and about the world after breast cancer. Abbi shared her fear of mortality and of how her death would impact her mother. I could see her sadness in contemplating that possibility. This seems to fit the experience of *'other-relatedness'*, which takes place during illness as patients' embodied concerns for others are said to lead to the development of empathic relationships (Frank, 2013).

Another important point was Carol's mistrust in her own body as she talked about being quietly attacked by it. Such a form of self-betrayal caused her intimacy issues as she reported a complete loss of sensitivity after the mastectomy (Larkin et al., 2015). On a similar note, Deanne described a difficulty in negotiating interpersonal relationships when seeking a romantic partner also due to intimacy issues. She did not have a reconstruction and reported that intercourse forced her to refocus on the empty space in her chest. The reminder of that loss seemed to make Deanne self-conscious about her appearance as she was confronted with her absent breast (Slatman, 2014).

Fiona's response to the lack of predictability in life after illness was to shift from her healthy status as a doctor by embodying her new ill identity as a patient. This perhaps reflected her way of managing vulnerable feelings by means of bringing some predictability in the face of uncertainty within illness. Carel (2012) proposes that adaptability in illness is not an uncommon response in relation to changes in the body and its functions, adding that the ill person needs to find meaning for their suffering and new limitations. Elena responded to vulnerability by acknowledging feeling bereft with regard to the end of professional care

follow-up. She shared that she was keen to continue having professional follow-ups even though she had regained her wellbeing and was no longer ill. These findings offer a means to better understand the need for professional care, supporting theories regarding the need for psychotherapy for those struggling to come to terms with the drawback of illness (Anllo, 2000). Thus, the uncertainty experienced in this *'Vulnerable Self'* position speaks most of all about holding difficult feelings of fear, sadness and unpredictability in the face of changes brought by the illness, but also about how to respond to such unexpected changes. Macmillan Cancer Support suggests complementary therapies (physical, psychological, etc.) for patients struggling with end of cancer treatment and the uncertainties that can arise during this phase (MacMillan Cancer Research, 2018).

Participants' *uncertainties* gave rise to doubts about self-concept with regard to how others would perceive them. *'Other's gaze'* is the last stage of participants' changes in perception about self, others and the world. It encompasses my participants' concerns, attitudes and perceptions of themselves and on how others might view them after the body changes – mostly regarding mastectomy. It includes feelings of being exposed physically and emotionally to scrutiny and potential rejection following changes in appearance, as well as the doubts about whether they will still look attractive in their partner's eyes.

Throughout the extracts, it was possible to identify a strong trend across all participants with regard to unwanted changes in appearance being linked to self-worth, provoking vulnerable feelings of rejection and inadequacy. Deanne's experience of self-worth, for instance, seems linked to a sense of what the ideal feminine portrayal should be like. She shares her dissatisfaction with being left with only one breast after mastectomy. Her perception of a damaged self-image gave rise to doubts about whether she would be perceived as sexually attractive by men, in particular when she compared herself with non-mastectomised women. Heather was also concerned about relational changes as a consequence of her being modified to the point where her husband might have found her unattractive. Similarly, Abbi reported feeling self-conscious about hair loss after treatment. Although she described feeling okay with the changes endured (hair loss and scarring), when it came to her romantic relationship, the dynamics became more complex. Abbi said she felt something was not well, elaborating that she noticed her partner withholding his gaze, which in turn she interpreted as his difficulty in being faced with her scarred and unfeminine looks (bald). Deanne's and Abbi's sense of self-image seemed to be heavily influenced by social norms

about what a healthy and good-looking woman should look like. Eichenbaum and Orbach (2012) explore that the feminine ideal in contemporary society is illustrated by high physical standards of perceived beauty. Although cultural differences are found across the world, mostly women are expected to look a certain way as portrayed in the media (skinny, young, large breasts, long hair, make up, neat, etc.), and to be sexually attractive for the male gaze. When they compared themselves with these often impossible to achieve ideals of feminine beauty and sexiness, my participants invariably felt inadequate.

Barbara's way of coping with the loss of cleavage and other changes in her chest area after mastectomy was to adapt the way she dressed as a means to conceal the changes from others. Interestingly, like Abbi, Barbara was also content with having the mastectomy, to the point where she refused a reconstruction. However, when it came to being subject to the gaze of others, Barbara felt the need to hide less acceptable parts of her appearance (Eichenbaum & Orbach, 2012). In contrast to Barbara's self-satisfaction with not having a reconstruction, I found in Carol's extracts feelings of sadness and inadequacy for having not had that option. A study by Marshall and Kiemle (2005) found that reconstruction was found to be a suitable option (when available) in improving self-image and subsequently providing women with a sense of appearing normal and symmetrical initially for partners and subsequently for themselves.

Like the other participants, Elena also experienced the stress of looking acceptable to other's gaze, though Elena seems to have taken a more assertive approach, sharing that she had the urge to see her scarred body and soon after showed it to her partner. That need to look at and show her scars seems to have been Elena's way of managing any issues as quickly as possible rather than concealing or postponing a potential rejection from her partner. Boquiren et al. (2016) define body image as *"a highly subjective mental representation, not only of one's physical appearance, body, and attractiveness but also of one's perception of overall health and functioning"*. Mastectomy and scarring are known for having a negative impact on body image as they hold implications for female sexuality and identity, being frequently associated with appearance dissatisfaction, feelings of shame, loss of attractiveness, and an altered sense of femininity (Boquiren et al., 2016). Such emotional experiences can be prejudicial to women's inclination to connect intimately with partners (Brédart et al., 2011), subsequently lowering the quality of sexual intimacy and wellness (Arroyo & Lopez, 2011).

The *'Vulnerable Self'* expresses power struggles in relation to the events unfolding after illness, reflecting participants' *'uncertainties'* about what the future holds, as they move into the often unsettling role of a patient. The fear of *'other's gaze'* or – in other words – of being rejected, and the desire to be accepted despite significant changes in their physical feminine appearance, are also expressed in this position.

2.3. Major Theme III – 'Coping Self'

The *'Coping Self'* is the third and final identity recognised in the data. It is where I identified participants' need to gather their remaining emotional resources following a phase of high vulnerability in order to continue their journey into regaining balance in their lives and re-establish wellbeing.

Abbi presented a survival mode in the form of rejection of the vulnerable feelings she expressed earlier. She seemed to be fighting the ill role of being a patient, as she saw it as a weakness, however contradictory that may seem in comparison to her early accounts about surrendering control to the care of doctors. This can be interpreted in the light of trauma when clients often fear experiencing psychological hurt, namely anxiety and sadness (Van der Kolk, 2014).

Fiona and Heather seemed to share similar views to Abbi when it came to manage the difficulty of fragile emotional states. This may be reflected in the presented transcripts, where their feelings were not even named. Both participants described their way of coping as resorting to a level of overlooking/rejection of painful feelings. Langellier and Sullivan (1998) provide a frame for understanding this through the examination of the 'breast talk' within women's illness (breast cancer) narratives. Fiona described how she was willing to engage with her illness by *"talking [in] purely medical"* terms to prevent engaging with the psychological pain of experiencing difficult emotions. I also considered her professional context; perhaps, due to her role as a medical doctor, Fiona was comfortable with the breast cancer jargon as that was the narrative she was familiar with prior to her illness. Although, she stated that her experience of illness could be accessed safely through a professional standpoint and removed from emotions. Fiona's accounts support Langellier and Sullivan's (1998) argument that the use of medicalised language is an abstract and detached way of approaching breast cancer safely without addressing emotional issues.

Additionally, Fiona shares Elena's concerns about self-protection if she were to take her partner to appointments, describing that she would have to cater for his needs of understanding the jargons and perhaps be *"looking after"* his potential emotional responses (Eichenbaum & Orbach, 2012). Also remarkable was Heather's description of *"hiding in an intellectual place"* while waiting for the test results. Anllo's (2000) findings support the suggestion that during diagnosis clients who resort to some level of denial retain a sense of wellbeing.

In contrast to Abbi, Fiona and Heather, Carol seems to acknowledge that overlooking vulnerable feelings leads her to appear to be coping well. However, she acknowledges that below that superficial *"veneer of coping"* that she successfully presents to others, she is still struggling emotionally to cope more adaptively. Likewise, Deanne seems to have adopted a strong, self-protective posture, by managing her feelings through the embodiment of the mythological figure of an Amazon – the single-breasted female warrior. I understood this creation of the Amazon figure as her taking a physically and emotionally protective posture to maintain a façade of strength while she walked tall into recovery. Deanne and Carol seem to have chosen a way of coping that protects them from external stressors (breast cancer) in order to re-establish a sense of physical and psychological security. That coping stance seems to have helped them in managing the experience of change in their physical abilities and adaptability to distress (Carel, 2012).

Elena's experience reinforces Abbi's survival mode thread and adds a social aspect to the *'Coping Self'*. Through Elena's accounts it seems clear that she must overcome vulnerability because she *"can't afford to fall apart"*, otherwise the family system may collapse. I interpreted *"falling apart"* here as embodying her painful feelings, which could lead to a failure in looking after her family (Eichenbaum & Orbach, 2012). Soon after that comment, Elena seems to engage with angry feelings, showing a low tolerance towards conforming to the stereotypical role of mother and wife imposed by society's structure – a role where women are expected to cater for everyone above and beyond their own emotional needs and means, despite their own circumstances (Eichenbaum & Orbach, 2012). She reflects on how her husband needs to gather himself and remain strong – meaning self-contained – so she doesn't have to be the only one doing it for the family. I can see a conflict between what Elena thinks she should offer and what she actually has available to offer with regard to the *"emotional work"* to be done collectively. Despite her willingness to spare the feelings

of her husband and children during her illness, I can sense a feeling of being pressured to cater for them while experiencing a lower level of emotional resources available to do so at this point.

This relational dynamic may be understood in the context of past research on intimacy and sexuality within partnership issues specifically. Hordern's (2000) study describes husbands' feedback about feelings of inability in coping with their wives' (breast cancer) needs, as these vary frequently and may include social, domestic and professional difficulties. In Hordern's study, the husbands' perspectives offer a one-way dynamic, which illustrates a social requirement of gender roles whereby women give more than they take in partnerships. Eichenbaum and Orbach (2012) argue that women are raised to be always in connection with others. As such, an important part of this gendered role is to be attuned to others' needs (*"emotional antennae"*) – however often needs may change. Arguably, this social expectation is damaging to women's wellbeing and to the overall family dynamics as the man is given a specific importance in the social realm (being the breadwinner) rather than also taking an emotionally attuned responsibility within the family life. Among the found consequences of such an attitude is that in challenging circumstances women end up stretching themselves too thinly for the collective good and end up neglecting their own needs (Eichenbaum & Orbach, 2012).

After the stage described above, participants began a process of *'comparing losses'*. In that stage they attempted to make sense of this emerging identity – *'Coping Self'* – while considering all experienced changes compared to those of others, and also compared to their former healthy identity. During this comparison, participants began to consider the value of sharing experiences, accessing support in regaining a lost sense of wellbeing, and acknowledging the magnitude of the hardship experienced in illness.

Abbi shared a painful acknowledgement of the hardship she endured throughout illness in comparison with her colleagues who – according to her accounts – expressed non-threatening life issues. Abbi seems to have experienced anger when hearing others' life complaints in comparison to her situation as a breast cancer patient trying to stay alive and recover health. Though she was angry, Abbi also resorted to emotional self-regulation as a way of re-establishing empathy; her situation was not necessarily harder or easier but rather different from her peers (Burman, Green, & Shanker, 2015).

Barbara expressed her realisation that talking to a professional can help. She said that she chose to keep her experiences fairly private but her reasons for this were unclear. Perhaps if I had more specific questions about coping, I could have gained a deeper understanding of it. As a counselling psychologist, however, my interpretation revolved around the value of sharing painful experiences as a way for Barbara to make sense of and process her feelings in a therapeutic setting. Past findings convey the importance of psychological therapies as a valuable tool in helping breast cancer patients manage an altered sense of self, low self-esteem and communication issues with sexual partners (Fobair, Stewart, Chang, D'Onofrio, Banks, & Bloom, 2006).

This also ties in with Heather's experiences of managing sexual intimacy issues linked to body image in her marriage. These findings offer a means to better understand the role of clinicians in encouraging and maintaining communication in relationships (doctor-patient/patient-partner(s)), supporting past research on improving psychological adjustment to foster women's wellbeing after mastectomy (Male, Fergus, & Cullen, 2015). Male and colleagues (2015) also argue for greater provision of specialised psychological services to be made available for breast cancer patients.

At this point, the *'Coping Self'* is trying to find the available systems (family, partners, friends, psychological support) to start *'recovering'* balance by returning to or recreating a fully functioning identity. The *'Coping Self'* is also comprised of this important part of women's intrinsic need to try to come to terms with the recovery from such serious and life-changing illness.

Carol described to me how she used a social media platform as part of her network of support, to share experiences with other people who had the same diagnosis. Although she reported having a positive experience with regard to exchanging information, she also mentioned the platform's limitation in terms of the nature of the information shared and her concerns about over-sharing online. Social media may be a suitable platform for those who do not wish to be seen but want to be heard and to hear others' stories. As a researcher, while doing an online search, I found a number of informal testimonials were available but formal research on the value to social media was insufficient. Attai et al. (2015) recently explored the effect of Twitter on the education and support of breast cancer patients using

a survey. Respondents reported increased knowledge and decreased anxiety through taking part in this social platform.

The role of social support is undeniable when it comes to improving the quality of life in breast cancer patients (Kim, Han, Shaw, McTavish, & Gustafson 2010) and its effects can be found across a variety of domains; lower levels of depression (Finch, Okun, Pool, & Ruehlman, 1999), improved social adjustment (Dunkel-Schetter, 1984), increased self-esteem (Feather & Wainstock, 1989) and the choice of active coping strategies (Kim et al., 2010). These studies raise concerns about the accuracy of information exchanged in online groups and whether it would be the responsibility of healthcare professionals to promote such forums. Schover, Yuan, Fellman, Odensky, Lewis and Martinetti (2013) conducted a randomised control trial to test the efficacy of internet-based intervention for cancer-related female dysfunction in comparison to the same intervention added to brief counselling. The intervention offered was online education and guidance for psychosexual-related issues. Results showed an improvement in quality of life in both conditions (with added counselling and without); however, sexual function was greater for those offered therapy in addition to online support.

Heather and Fiona seem to focus on the idea of finding suitable social support, which can provide the necessary space and information not only to help make sense of experiences but also to help build a narrative for illness and recovery. Although Heather had a couple of sessions of counselling during illness and was also offered an online self-help resource, her accounts suggest that she could benefit from one-to-one therapy (individual/couples) to help foster her recovery and consequently improve her quality of life (Reese, Porter, Bober & Lapore, 2017). Fiona also had four sessions of counselling and expressed the relief at having a space to express her feelings and to get it off her chest. Heather's accounts about therapy, when she says, *"So, it was useful trying to just talk around it, and go but we haven't got the right words for this, how do you describe your feelings?" (Heather, 151),* are in line with past research suggesting that one important struggle cancer patients experience is with regard to making sense of the diagnosis and drawing meaning from the circumstantial changes (Willig, 2011). Additionally, Heather discussed how keeping communication open with her partner through couple's therapy was helpful in managing intimate issues in unexpected ways (Fobair & Spiegel, 2009). She described having found a whole spectrum of intimacy that was not considered prior to therapy. Heather also describes the embodiment

of intimacy as she discloses ways of being intimate that do not involve intercourse, such as foot massages and holding hands.

Maclaren (2014) discusses the nature of intimacy of touch in relation to others within a phenomenological framework. Maclaren (2014) argues that in order to establish intimacy, individuals need to experience a sense of a shared physical world. Results from neurophysiological research show a neural pathway that highlights pleasurable stroking, indicating that human bodies are wired for social intimate touch. While exploring the need for intimate touch in interpersonal relationships in individuals with some form of body limitation (disability or chronic illness), disruption to couples' intimacy and to one's own intimacy with the world is evident as the body mediates physical embodiment. In Heather's case I interpreted her need for physical closeness beyond penetrative sex as her need to embody intimate touch, perhaps as an attempt to reach out for her partner while co-creating a new experience within her body limitations.

Deanne's experience of rebalancing and refocusing within herself while recovering a healthy identity was a challenging pursuit that involved regaining ownership over the Self (mind and body). She shared her reflections on seeking within her body the necessary knowledge to cope with changes. Van der Kolk (2014) proposes that recovery from trauma means developing the ability to trust and to rely on one's feelings and knowledge about their processes while managing any difficult feelings that may arise. In order to access our inner world, some level of body awareness is necessary. Shifting focus to physical sensations allows the recognition of internal emotional processes and insight into how to manage them (Van der Kolk, 2014).

This study discusses its findings by building on the qualitative and quantitative research on identity change, self-image and sexual intimacy after mastectomy and relating this to women's wellbeing. The first step is the *Ill Self,* conveying the sudden change in health status from healthy to unhealthy and illustrated by the *pain* (physical and psychological) and *body changes* that participants were submitted to and which caused changes in self-image. The second step is the *Vulnerable Self*, expressing power struggles as participants decided when to surrender and when to take *control.* At this second fragile stage, women were faced with a hostile climate full of *uncertainties* while being exposed to *other's gaze,* provoking a change in self-concept. The final step, the *Coping Self*, was discussed through a *warrior*

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figure, which was identified as a survival mode activated to manage unwanted vulnerable feelings. The *warrior* seems to have emerged based on the need of participants to cope with a changed and fragile sense of self. The difference between actual warriors and my participants is that these women were not prepared for combat but rather were taken by surprise. Despite that, they fought with the 'weapons' they had available. This final major theme also talks about women's inclinations to *compare losses* by taking stock of what was lost/gained in the process of illness and discusses their need to continue to thrive and move towards *recovery* and full functioning despite all the mishaps along the way.

3. Strengths and Limitations of the Present Study
3.1. Strengths

While considering the strengths of this study, I reflected on my skills as a researcher as well as on the strengths of the method itself. Firstly, as a researcher, one of my primary concerns during this project was the participants' wellbeing. It was important that participants felt safe and willing enough to share their stories openly. I wanted to come across as approachable and relatable rather than being seen as part of the clinical staff and I believed that was a helpful approach in ensuring the quality of the data gathered, as participants expressed their contentment in talking to me during the interview. After exploring options with my supervisor, I decided to set a friendly and light tone by developing as much rapport as possible through the phone triage. That was when my humanistic skills of unconditional positive regard, congruence and empathy came into play relationally for the first time in this process. While exploring the experience of empathy in counselling psychology, it is inevitable to talk about the Rogerian humanistic approach, which is broadly understood as the therapist entering the client's world (Rogers, 1975). It consists of the relational process of the therapist's sense-making and reflecting back their understanding of a particular phenomenon experienced by the client. The Rogerian concept of empathy in clinical practice can be translated and applied in the subjective relationship between researcher and participant. In practice, empathy was an important tool, used as a way of entering my participants' world in the context of my research. It was a helpful means of offering my interpretations of participants' lived experiences of identity in relation to illness and within that of exploring how participants experienced their bodies.

Secondly, due to its in-depth focus on the meaning of individual lived experiences, the qualitative nature of this research is a strength in itself. It adds an in-depth analysis of the

experience of women's sense of femininity and sexuality after mastectomy by building on the existing quantitative data on the topic. The phenomenological approach of IPA caters for the topic's sensitivity by enquiring into participants' experiences of a phenomenon and for these reasons has been found to be increasingly useful in research studies relating to illness and quality of life (Van Manen, 1990; Moustakas, 1994). IPA was helpful in providing accounts of the psychological reactions of my participants when faced with the changes in their healthy identity. My results are congruent with suggestions made by Keitel and Kopala (2000), who identified affect and mood as important assessment targets in breast cancer patients.

The gaps left in previous generalised quantitative results were addressed in the present study by giving voice to women's shared embodied experiences of identity change, self-image and sexual intimacy after mastectomy. These women explored meaning within an unexpectedly emerging new identity and as they addressed new functions to their bodies: previously healthy and now ill. Thus, the present study tells a story across time, where women recovering from breast cancer were able to explore their emotional and physiological reactions as well as their coping skills and the difficulties triggered at the moment of diagnosis and throughout rehabilitation. Although quantitative findings present valuable data in general understanding in larger samples (Ganz, Belin, Desmond, Meyerowitz, & Rowland, 1999; Przezdziecki et al., 2013; Rosen et al., 2000), they lack personalised knowledge of the experiences of femininity and sexuality in women diagnosed with breast cancer, including their individual and relational struggles.

3.2. Limitations

One of the limitations of the present study lay in my decision to select a purposive sample, as per Smith, Flowers & Larkin's (2009) suggestions. Despite that being regarded as the best option in an IPA due to its aim of investigating the experiences of a small (in this case, eight participants) and fairly homogenous group, it limited the generalisation of my findings (Smith et al., 2009). My participants were all women above the age of 18 who had undergone a mastectomy after a diagnosis of breast cancer. The recruitment process occurred mainly through placing adverts within my university grounds, which in turn left me with a sample of participants from a similar socio-economic, ethnic and educational background. My participants were all heterosexual and currently sexually active – either in a committed or a non-committed relationship setting with one or more partners.

If I'd had more time and resources, I could have explored a sample of women of varied sexual orientation, and from a varied socio-economic, cultural, ethnic and educational background. I believe that would have provided a broader knowledge about commonality and dissimilarities across experiences of femininity and sexuality after mastectomy.

4. Reflexivity

In research terms, reflexivity implies critical self-awareness about how the researcher impacts the outcome of research due to their own positioning and assumptions when searching for meaning in the data (Finlay & Gough, 2003).

4.1. Methodological reflexivity (strategic)

Although I am not an experienced interviewer, I ensured that I was fairly familiar with the topic of breast cancer in the hope that this would help me to begin imagining what it must have been like to go through such an illness. I was conscious about preparing for my interviews by acquainting myself with the relevant definitions of femininity, sexuality and the concept of embodiment as I was looking for both physical and emotional responses. It was important to me that I knew some oncological terms but not all and not in depth. My main aim with this attitude was to remain curious and that proved to be a helpful tactic when probing my participants to elaborate further in the meaning they attributed to experiences. During the initial phase of diagnosis, oncologists frequently made use of clinical and technical jargon and not being overly familiar with this helped me in enquiring what they meant and in understanding how participants made sense of the jargon while their healthy identity was being lost.

As to the interview schedule, I wanted the interview to be a conversation rather than a formal meeting to avoid participants feeling that they were not giving the 'right' answers to my questions. I was attentive about not making too many remarks during their answers to avoid interrupting their natural flow. Instead I used my body language to show that I was present every step of the way. Although my interview schedule was on my lap, prior to starting the interview I very briefly shared it with participants and did not use it as a checklist. I carefully studied every question and deviated slightly from the original order of my questions at times, as the participants would answer some questions before I asked them. Instead, on such occasions I used my prompts to encourage them to speak further about a particular topic. I tried to keep the interview within the script but without pushing my own agenda. I was also

aware of my needs as a researcher to gather as rich data as possible within the topic while encouraging participants' own exploration of feelings. Initially it was challenging to separate my practitioner identity from my researcher role but doing a pilot interview and having the university as the setting of my interviews definitely helped me.

It was a concern of mine that I gave clear and simple directions on how to get to the interview location to avoid raising anxieties. The place where we met had to be safe, quiet and contained. I chose rooms that were small, carpeted and I produced a door sign to avoid interruption as the interviews were carried out at my university. I dressed in a smart-casual manner and kept my hair up in a bun after meeting my first interviewee, who was still fairly bald from chemotherapy. As a way of making participants comfortable I spent extra time on the introduction prior to the research commencing and the digital recorder was on.

At the end of the interview, I offered closure by using the debriefing sheet as a prop and I offered participants as long as they needed to gather themselves. Many participants were struck by their ability to engage with emotions linked to their illness and experienced several years earlier. I ensured that each candidate had enough time after the interview to discuss any concerns that could have arisen from the interview and that they knew where to go should they need formal emotional support.

While considering the quality of my work, I explored issues of data validity and rigour. Smith et al. (2009) argue for the need to assess validity and reliability adequately in qualitative methods, despite these concepts being traditionally connected to quantitative methods. In the methodology chapter, the readers can find a detailed description of my methodological considerations, based upon Yardley's (2000) four criteria, namely *'sensitivity to context', 'commitment and rigour', 'transparency and coherence'* and *'impact and importance'*. When considering a way of establishing *'commitment and rigour'*, I decided to use a pilot interview before collecting the actual data. During the pilot I had the opportunity to explore and refine my questionnaire to allow participants to begin talking broadly about their experience of diagnosis and slowly narrowing it down to the research question. Choosing IPA as the most suitable methodology ensured *'sensitivity to context'*. Although this qualitative approach has been widely used in counselling psychology, I found that if I wanted to interpret rich data while keeping my participants at the core of the study in the context of a topic, which is borderline health psychology, IPA was the most suitable to investigate the experience of

illness, as argued by Smith (1996). The practical implication of my study was an important point that I considered from the start. *'Impact and importance'* is demonstrated through my consideration of the implications for the field of counselling psychology of course, but also for other healthcare practitioners and services. The illustration of my analytical steps through tables and pictures, in accordance with Smith et al. (2009), shows my commitment to *'transparency and coherence'*. The publication of my methodological and embodied reflections (see also the methodology chapter) as per Finlay's (2011) suggestions adds extra insight and therefore transparency to my thinking patterns and felt-sense of the whole project, while allowing me to bracket my previously held assumptions.

4.2. Embodied reflexivity (personal)

When considering my role as a counselling psychologist in clinical practice, I have been acutely aware of continuously developing my ability to critically reflect on my position in the therapeutic relationship (HCPC, 2018). As a way of applying such skill in this research project, I reflected on how I would use myself as an intrinsic part of this interpretative process. I approached the data using Finlay's (2005) phenomenological concept of participant-researcher inter-subjectivity in reflexive *'embodied empathy'*. This concept regards the engagement of reflexivity regarding the embodied inter-subjective relationships between participants and researchers (Finlay, 2005). Finlay (2005) explains that this process has three interpenetrating layers of reflexivity: *"connection of (the other's embodiment to our own); acting into (other's bodily experience); and merging with (the other's bodily experience)"*. The first layer – *connection of* – is about attunement to the other by attending to and using one's own bodily reactions. The second layer – *acting into* – is focused on the relational dynamics based on empathic responses between researcher and participant. The third layer – *merging with* – requires a *"reciprocal insertion and intertwining"* of others in oneself and of one in them (Merleau-Ponty, 1968); in other words, it is the process of successfully gaining insight into the other and mutually attending to one's own awareness (understanding the other and self-understanding).

According to Merleau-Ponty (1962), *"the body is the vehicle of being in the world",* and therefore the means by which we experience and subsequently make sense of the world within and around us. One's own embodied consciousness allows the space to also perceive and understand the other. In practice, Merleau-Ponty's ideas refer to the embodiment, insight and self-reflection in the process of phenomenological research. Thus, the empathy

experienced by the researcher in the research process is about the inter-subjective embodied feelings that overarch the researcher-participant experiences. That is how the researcher engages with the participants' described experiences and inhabits their own and the others' feelings (Finlay, 2005). After having explored the theory of *'embodied empathy'*, I share my embodied reflexivity positioning with the reader as an intrinsic layer of the meaning making process and as a part of the relationships co-created with participants. This practice is essential for the research experience as part of the hermeneutic reflection (Finlay, 2005).

It is a natural human tendency to ascribe meaning to all that is experienced. That tendency takes place as self-awareness but also from an awareness of the world around us. The significance perceived in our experiences is rooted in our observation of patterns as they relate to us. A particular situation has the power to inform us about life as it exposes us to something unfamiliar. Events and others touch us emotionally, yet our initial impressions of a given experience may not fully reveal the true significance of these people and events and that is due to the multi-layered nature of experiences (Maclaren, 2014). Focusing on what it means to be human belongs to the realm of phenomenological psychology (Finlay, 2006). The phenomenological approach resonates with my understanding of the world and my understanding of the clinical training I have received so far. The approach that I have been closely connected with throughout my training and clinical experience is the humanistic approach. That has been the backdrop of all my clinical practice and research work from the beginning and is still present today. I see it as a holistic view of the person, who is trying to gain insight into their intrapersonal and interpersonal world. It is an approach that is empowering of the individual and does not impose meaning or any particular set of rules which one should live by. Humanistic psychology is closely aligned with the phenomenological framework, so carrying out my research using this method came naturally to me, given the type of enquiry I had.

My intention was to interpret women's experiences of femininity and sexuality in the context of illness. Doing that by holding a sense of genuine curiosity and while temporarily suspending my assumptions and any previous understanding seemed natural to me. I tried to bracket my preconceptions by setting them aside, so I could remain open to the phenomena and to my participants while looking for emerging themes. Through a research diary, I have been aware of my position as a female researcher-practitioner and of how that

may have encouraged the creation of a rapport with my participants. Further, my gender and role as a student may have impacted positively the data collection as I felt – and many participants confirmed –their empathy with my position as a female student. Tracking my own processes (feelings and thoughts) throughout the research project is in line with Finlay's (2011) suggestion of maintaining a consistent process of reflexivity. This acute concern to focus on reflexivity delayed the analysis and write-up process by a few months, causing me a great deal of stress, which I embodied through the development of a back/neck muscle inflammation and also some frustration. As my participants unfolded their stories, however, I felt as though I was part of their story and I was to an extent co-producing the findings. It was as if we were working collaboratively for the results of my research project. I was concerned to understand my participants embodied lived experience through the meaning they attributed to femininity and sexuality via their relationship. I interpreted their self-identity developing as they embodied the experience of illness. I tried to capture the essence of what they were living at that point in time but also as they reflected back to me on their memories of it. We were together in that present moment while being tied to events that happened in the past because my participants were in the recovery phase of breast cancer and there was a sense of becoming (ill/healthy).

Unpicking the layers of my participants' experience of illness and relationships within that was an insightful and interesting exercise that caused me a range of feelings including affection and caution. My interpretation of their situation was based not only on important descriptive facts but also on my feelings, beliefs, and values. From discussions with my colleagues, I quickly realised that the meaning of an event can change when viewed in another context. My participants were describing their past experience with some level of distance but also as if they were able to re-experience it all again by sharing it with me. On many occasions, but in particular soon after the interview meeting, I could physically feel their pain, discomfort, anxieties and sadness as if they were my own and I felt deeply empathic towards them. It was a concern of mine, though that I stayed rooted in their description as much as possible while interpreting their meaning making. It felt like a fluid and ever-evolving meaning making process. As many of my participants shared how surprised they were to be able to recall so vividly experiences that had happened years ago, I felt that my skills were sufficient to offer a space where they felt safe to revisit their painful memories safely. That realisation filled me with an unexpected sense of achievement, which was deeply touching in the presence of these women who were willing to bare their

vulnerabilities to me. I hope that the impressions I gained intellectually and emotionally from my participants' experiences, and refined after exploring their significance, can add richness and texture to this project.

5. Practical Implications for Counselling Psychology Services

According to the HCPC Standards of Proficiency for Practitioner Psychologists (2015), the ninth domain concerns the practitioner's *'ability to work appropriately with others'*. Within that, I reflect on my study's practical implications for counselling psychology services based on the analysis of my study's findings, which indicate participant's need for a holistic approach to treatment. In practical terms, that translates into clients' concerns about their psychological processes (issues with identity change, self-image and sexual intimacy) being regarded simultaneously and as highly as the physicality of their illness (removing and treating the cancer through chemotherapy, radiotherapy, mastectomy and medication).

This question triggered me to consider how this would fit within a frame of clinical partnerships between counselling psychologists, oncologists, nurses and other relevant healthcare professionals. My key findings suggest the need for building and maintaining professional relationships both as an independent counselling psychologist and as a clinician working in conjunction with other healthcare professionals/teams, although such collaborative efforts will not be complete without the close engagement of clients in the creative process of assessments and formulation. Designing a holistic treatment plan based on overall client needs and that accounts for physical and psychological needs of service users is of utmost importance. The use of psychological interventions adjacent to medical treatment have been found to be helpful during the adjustment phase for the often-inevitable physical changes brought about by cancer treatment (Conley, Bishop & Andersen, 2016). Additionally, the efficacy of a body–mind–spirit therapy in treating anxiety in a group of breast cancer patients was found to be effective, showing that a holistic approach can be very successful in managing overall distress caused by the loss of health (Liu et al., 2008).

Arguably one of the most important roles for a counselling psychologist in this context lies in the mediation and encouragement of an open communication channel between service users and other healthcare practitioners. Despite the current information given in the media and through the breast cancer clinic via leaflets, participants still spoke extensively about the lack of practical knowledge about the steps following diagnosis and into treatment and/or

surgery. That could be due to the shock of being diagnosed and the sudden changes in self-concept and routine. A number of studies have explored and discussed the limitation in communication of needs between clinicians and patients. Breslau (2003) found that clients might feel higher resistance in disclosing emotional content to clinical staff due to the perceived lack of communication skills from clinicians. Marshall and Kiemle (2005) proposed improvements in the communication between healthcare providers and service users regarding the possible changes relating to body image, self-concept and relational difficulties that a patient could experience as a consequence of mastectomy and cancer treatment. My research results show that largely, the quality of sexual health services offered at present is limited and generic. In a more recent study, Pinto (2013) showed that clinicians and patients expect each other to bring up the subject of sexuality and that may suggest some difficulty from both parties in addressing openly this important aspect of wellbeing often transformed in illness, in particular sexual issues in female patients who are not in a committed relationship.

Based on my study's results and past empirical evidence, I draw my rationale, which illustrates the importance of embodiment versus the fragmentation of the healthcare offered today. A holistic support that attends to the physical and psychological needs of clients can improve significantly patients' relationships and perceptions of self and others following physical and psychological transformations. Recently, Male et al. (2015) suggested that the healthcare professionals should become more aware of the needs of the breast cancer patient population in order to draw a more comprehensive care plan, which includes suitable psychological interventions according to individual needs. Therefore, attending, assessing and treating breast cancer patients' needs via a multimodal approach that accounts for the biopsychosocial domains was proposed (Male et al., 2015).

Based on the findings of this research, and reflecting on ways of addressing these gaps, I identified a few ways of informing psychological practices in the context of providing a holistic care for women struggling with identity change, self-image and sexual intimacy after mastectomy:

- **III Self**

While exploring the meaning of this first major theme, it was possible to identify the need to offer individual psychotherapy from the moment of diagnosis and throughout recovery.

Individual therapy can successfully support clients with their emotional needs in managing unwanted changes in sexual health in addition to addressing the transition in self-concept from health to illness and recovery phase (Andersen, 2009). Individual therapy was found to be a good option available for patients in need of a private and confidential space to explore psychological struggles. More specifically, existential sex therapy is an opportunity for women to address psychosexual struggles after mastectomy. It offers patients a reflective space for breaking down the barriers between normality-abnormality relating to sexual functioning and instead facilitating the exploration of meaning related to the experience of 'symptoms' beyond its physicality (Barker, 2011).

- **Vulnerable Self**

In the Vulnerable Self major theme, I found significant concerns from women who felt exposed in relational dynamics after so many changes to the integrity of their physicality and psyche. In such cases, couple interventions could be an effective way of normalising feelings of uncertainty, struggles with control and fear of other's perceptions after mastectomy and sharing experiences by fostering effective communication relating to relational psychosexual difficulties. Perz, Ussher and Gilbert (2014) sustain that open communication between couples is a predictor of better relational adjustments after the experience of breast cancer.

- **Coping Self**

The final major theme found – the Coping Self, illustrates the resources that mastectomised women found helpful during the recovery phase of their illness as they were striving to regain balance and recover their healthy identity. The power of collective sharing and mutual support was evident in maintaining hope and fostering resilience though illness. One suggestion includes the offer of support groups facilitated by counselling psychologists, to address the found limitations in communication between clinicians and patients. This would be a way of offering a contained and safe space for reflection on ideas about adaptive coping after the changes (physical and psychological) brought by illness. It could also offer a platform for clients to exchange experiences through the comparison of loses and the exploration of difficult feelings relating to the temporary loss of functioning in various roles (e.g. as a mother, as a partner and as an employee) as a result of physical illness. Matthews, Grunfeld and Turner (2017) carried

out an extensive literature review on psychosexual interventions for mastectomised patients and concluded that group CBT outcome measures were highly significant in improving patients' self-esteem. Group therapy seems paramount for mastectomised women in need of a collective support system while recovering their quality of life after the illness is no longer an immediate threat to their lives.

The main practical implication highlighted by the present study is with regard to improving quality of life for women recovering from breast cancer. Multidisciplinary healthcare units may be the best option in dealing with the psychological and the physical complexities of illness, which were found to impact negatively patients' overall wellbeing through identity change, self-image and sexual intimacy.

6. Practical Implications for other Healthcare Practitioners

The latest version of the NICE Guidelines for healthcare professionals (2018) includes a brief section on supportive care for advanced breast cancer patients. It suggests the incorporation of *"assessment and discussion of patient's needs for physical, psychological, social, spiritual, and financial support"* (NICE, 2018). These recommendations should be put into place from the moment of diagnosis and reviewed at various stages of treatment (end of treatment, at relapse and/or during palliative care). When applied to individual cases, a key worker should be nominated to ensure appropriate adherence to the care plan (NICE, 2018).

Bearing these proposed guidelines in mind, and in a similar vein to the section above, I explored how other healthcare professionals could benefit from the present findings by incorporating them into their existing practice. My results are in line with the UK's government's agenda for care, which proposes a holistic approach to assessment and treatment of breast cancer as a way of ensuring quality of life. While considering my role of counselling psychologist working in that network of care, I believe the role adopted would be that of a facilitator who understands the patient's needs and the needs of any carers involved. Perhaps my role in this chain of professionals would be to communicate valuable feedback between clinical staff and service users. That would be based upon the multidisciplinary team's formulation of needs and communication would be made explicit as a way to promote sound clinician-patient relationships.

7. Future Directions

Considering the present findings discussed above and in the light of past research on the topic, some future directions are suggested. The qualitative in-depth results in the present study highlight women's concerns with regard to the need for a network of support that is holistic in its approach, in order to help with the management of changes in self-identity, self-image and sexual intimacy after illness. Similarly to the present findings, key results of past studies show that having a strong network of support throughout illness and also during recovery was a significant trend (Aldaz et al., 2018; Attai et al., 2015; Ashing-Giwa et al., 2004).

Although the present participants reported having a preference for one type of support over another, all women unanimously needed some type of support for their recovery process to be successful. Amongst the networks of support found were close family, friends and partners, as well as a broader environmental support from professionals such as psychotherapists, oncologists, nurses, online platforms and educational material provided by healthcare professionals or found online through independent research. This trend was highlighted within the '*Coping Self*' major theme and as that was the final position the participants adopted during the experience of illness.

It seems pertinent to continue exploring what are the best-suited options regarding the network of support in a variety of cases, according to what is available in different groups. For instance, the study by Adams et al. (2011) found that a group of younger women needed extra support with childcare resources whereas other studies pointed out that older women's concerns were focused on body image (Marshall, Lengyel, & Menec, 2014; Chrisler & Ghiz, 1993). These results suggest that different populations have different needs and assumptions relating to demographics (age, ethnicity, etc.). The assumption that body image can only be a concern for a younger population makes it difficult for older women to even approach the subject of discussing such issues with their doctors (Chrisler & Ghiz, 1993) and this could be challenged and further explored in future research. The identified experiences can provide additional psychological information to healthcare providers when considering the improvement and development of care in cancer clinics, regardless of the patient's age at the time of diagnosis. Thus, different groups experience psychological distress differently and issues regarding self-concept can be experienced at any point during

illness. The more knowledge gained and the more awareness promoted, the better informed healthcare professionals will be to respond appropriately to each case individually.

Lastly, future quantitative research could also explore whether the present findings hold for a larger group, and in-depth research could explore specific issues in certain demographics (e.g. differences and similarities in experiences for women in same-sex relationships; or women from different ethnicities and across ages).

8. Conclusion and Summary

Key findings of the present study reveal participants' embodied struggles with changes in identity (healthy-ill) after breast cancer, at diagnosis and throughout recovery. Participants reported their perceptions and reactions regarding identity change, self-image and sexual intimacy after mastectomy. My results are congruent with findings from the reviewed literature on cancer patients' experiences of illness (e.g. Aldaz et al., 2018). Participants' wish for a holistic approach to care from specialised services during treatment and recovery was noted. A gap in the provision of psychotherapeutic services in facilitating sensitive communication and following up the recovery of breast cancer patients was also identified within medical teams.

6. REFERENCES

Adams, E., McCann, L., Armes, J., Richardson, A. Stark, D., Watson. E., & Hubbard, G. (2011). The experiences, needs and concerns of younger women with breast cancer: A meta-ethnography. *Psycho-oncology*, 20(8), 851-861.

Al-Ghazal, S. K., Sully, L. Fallowfield, L. and Blamey, R. W. (2000). The psychological impact of immediate rather than delayed breast reconstruction. *European Journal of Surgical Oncology*, *26*, 17–19.

Aldaz, B. E., Treharne, B. E., Knight, R. G., Conner, T. S, & Perez, D. (2018). "It gets into your head as well as your body"/ The experiences of patients with cancer during oncology treatment with curative intent. *Journal of Health Psychology*, *23*(1), 3-16.

Almeida, T. R., Guerra, M. R., & Figueiras, M. S. T. (2012). Breast cancer repercussion in female body image: A systematic review. *Physis: Revista de Saude Coletiva*, 22(3).

Andersen, B. (2009). In sickness and in health: Maintaining intimacy after breast cancer recurrence. *The Cancer Journal*, *15*(1), 70-73.

Andersen, B. L., Yang, H. C., Farrar, W. B., Golden-Kreutz, D. M., Emery, C. F., Thornton, L. M., ... Carson, W. E. (2008). Psychologic intervention improves survival for breast cancer patients: A randomized clinical trial. *Cancer*, *113*(12), 3450-3458.

Anllo, L. M. (2000). Sexual life after breast cancer. *Journal of Sex & Marital Therapy*, *26(3)*, 241-248.

Arroyo, J. M. G., & López, M. L. D. (2011). Psychological problems derived from mastectomy: A qualitative study. *International Journal of Surgical Oncology*, 2011, 1-8. doi:10.1155/2011/132461

Ashing-Giwa, K. T., Padilla, G., Tejero, J. Kraemer, J., Wright, K., Coscarelli, A., … Hills, D. (2004). Understanding the breast cancer experience of women: A qualitative study of African, Asian American, Latina and Caucasian cancer survivors. *Psycho-Oncology*, *13*, 408–428.

Attai, D. J., Cowher, M. S., Al-Hamadani, M., Schoger, J. M., Staley, A. C., & Landercasper, J. (2015). Twitter social media is an effective tool for breast cancer patient education and support: Patient-reported outcomes by survey. *Journal of Medical Internet Research*, *17*(7), e188.

Barker, M. J. (2011). Existential sex therapy. *Sexual and Relationship Therapy, 26*(1), 33–47.

Beckjord, E., and Compas, B. E. (2007). Sexual quality of life in women with newly diagnosed breast cancer. *Journal of Psychosocial Oncology*, *25*(2), 19-36.

Benyamini, Y. (2011). Health and illness perceptions. In Howard S. Friedman (Ed.), *The Oxford handbook of health psychology*. Retrieved from https://doi.org/10.1093/oxfordhb/9780195342819.013.0013

Bloom, J. R., Stewart, S. L., Johnston, M., & Banks, P. (1998). Intrusiveness of illness and quality of life in young women with breast cancer. *Psycho-Oncology, 7*, 89–100.

Boquiren, V. M., Esplen, M. J., Wong, J., Toner, B., Warner, E., & Malik, N. (2016). Sexual functioning in breast cancer survivors experiencing body image disturbance. *Psycho-oncology*, 25(1), 66-76.

Boss, P. (2009). The trauma and complicated grief of ambiguous loss. *Pastoral Psychology*, *59*(2), 137 145.

Brédart, A., Dolbeault, S., Savignoni, A., Besancenet, C., This, P., Giami, A., ... Copel, L. (2011). Prevalence and associated factors of sexual problems after early stage breast cancer treatment: Results of a French exploratory survey. *Psycho-oncology*, *20*(8), 841-850.

Breslau, E. S. (2003). The continuum: Somatic distress to medicalization in women with breast cancer: Theoretical and empirical assessment." *Gender Perspectives on Health and Medicine*, 131-180. Published online 9 Mar 2015. Retrieved from https://doi.org/10.1016/S1529-2126(03)07005-X.

British Psychological Society (BPS) (2009). Code of Ethics and Conduct. Retrieved on the 10th June 2018 from: http://www.bps.org.uk/search/apachesolr_search/code%20of%20ethics%20and%20conduct

Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology & Health*, *21*(1), 87–108.

Burman, J. T., Green, C. D., & Shanker, S. (2015). On the meanings of self-regulation: Digital humanities in service of conceptual clarity. Child Development, 86(5), 1507-1521.

Cancer Research UK (2018). Breast cancer: Choosing between lumpectomy and mastectomy. Retrieved on the 18th November 2018 from: https://www.cancerresearchuk.org/about-cancer/breast-cancer/treatment/surgery/lumpectomy-or-mastectomy

Cancer Research UK (2011). Data on breast cancer statistics. Retrieved on the 10th June 2018 from: http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/breast-cancer#heading-Zero

Cancer Research UK (2018). Cancer statistics for the UK. Retrieved on the 18th July, 2018 from: https://www.cancerresearchuk.org/health-professional/cancer-statistics-for-the-uk.

Carel, H. (2011). Phenomenology as a resource for patients. *Journal of Medicine and Philosophy*, *37*(2), 96-113.

Carel, H. (2012). Phenomenology as a resource for patients. *The Journal of Medicine and Philosophy*, 37(2), 96-113.

Chivers, M. L., & Brotto, L. A. (2017). Controversies of women's sexual arousal and desire. *European Psychologist*, 22, 5–26.

Chrisler, J. C. and Ghiz, L. (1993). "Body image issues of older women", in Davis, N.D., Cole, E. and Rothblum, E.D. (Eds), Faces of Women and Aging, The Haworth Press Inc., Binghamton, NY, pp. 67-75.

Chua, A. S., De Santis, S. M., Teo, I., & Fingeret, M. C. (2015). Body image investment in breast cancer patients undergoing reconstruction: Taking a closer look at the Appearance Schemas Inventory-Revised. *Body Image, 13*, 33–37.

Cleary, V., Hegarty, J., & McCarty, G. (2011). Sexuality in Irish women with gynecologic cancer. *Oncology Nursing Forum, 38*(2), E87-E96.

Collins, K. K., Liu, Y., Schootman, M., Aft, R., Yan, Y., Dean, G., ... Jeffe, D. B. (2011). Effects of breast cancer surgery and surgical side effects on body image over time. *Breast Cancer Research and Treatment*, *126*(1), 167-176.

Conley, C. C., Bishop, B. T., & Andersen, B. L. (2016). Emotions and emotion regulation in breast cancer survivorship. *Healthcare (Basel, Switzerland)*, *4*(3), 56.

Curbow, B., Somerfield, M., Legro, M., & Sonnega, J. (1990). Self-concept and cancer in adults: Theoretical and methodological issues. *Social Science Medicine, 31*(2), 115-128.

Davidson, R. J., Kabat-Zinn, J., Schumacher, J., Rosenkrantz, M., Muller, D., Santorelli, S.F., ... Sheridan, J. F. (2003). Alterations in brain and immune function produced by mindfulness meditation. *Psychosomatic Medicine*, *65*, 564–570.

Dodge, R., Daly, A. P., Huyton, J., & Sanders, L. D. (2012). The challenge of defining wellbeing. *International Journal of Wellbeing*, 2(3), 222-235.

Doka, K. J. (1999). Disenfranchised grief. *Bereavement Care*, *18*(3), 37-39.

Donovan, K. A., Taliaferro, L. A., Alvarez, E. M., Jacobsen, P. B., Roetzheim, R. G., & Wenham, R. M. (2007). Sexual health in women treated for cervical cancer: Characteristics and correlates. *Gynecologic Oncology 104,* 428–434. Retrieved from https://doi.org/10.1016/j.ygyno.2006.08.009

Dougall, A. L., & Baum, A. (2001). In A. Baum, T. A. Revenson & J. E. Singer (Eds), *Handbook of Health Psychology* (pp. 709–725). Mahwah, NJ: Lawrence Erlbaum Associates.

Dowling, M. (2007). From Husserl to van Manen. A review of different phenomenological approaches. *International Journal of Nursing Studies*, *44*(1), 131–142.

Dunkel-Schetter, C. (1984). Social support and cancer: Findings based on patient interviews and their implications. *Journal of Social Issues*; 40:77–98.

Eichenbaum, L., & Orbach, S. (2012). *Understanding women: A feminist psychoanalytic approach*. New York: Basic Books.

Fatone, A. M., Moadel, A. B., Foley, F. W., Fleming, M. & Jandorf, L. (2007). Urban voices: The quality-of-life experience among women of colour with breast cancer. *Palliative and Supportive Care*, *5*, 115–125.

Feather, B. L., & Wainstock, J. M. (1989). Perception of post mastectomy patients. Part 1. The relationships between social support and network providers. *Cancer Nursing*, *2*, 293–300.

Finch, J. F., Okun, M. A., Pool, G. J., & Ruehlman, L. S. (1999). A comparison of the influence of conflictual and supportive social interactions on psychological distress. *Journal of Personality*, *67*,581–621

Fink, G., & Elsevier Freedom Collection EBA (2016). *Stress: Concepts, cognition, emotion, and behaviour*. London: Academic Press, an imprint of Elsevier.

Finlay, L. (2005). "Reflexive Embodied Empathy": A phenomenology of participant–researcher intersubjectivity. *The Humanistic Psychologist*, *33*(4), 271–292.

Finlay, L. (2006). Dancing between embodied empathy and phenomenological reflection. *Indo-Pacific Journal of Phenomenology*, 6, Special Edition.

Finlay, L. (2011). *Phenomenology for therapists: Researching the lived world*. Chichester: Wiley- Blackwell.

Finlay, L., & Gough, B. (2003). *Reflexivity: A practical guide for researchers in health*

and social sciences. Oxford: Blackwell Science.

Finlay, L., & Langdridge, D. (2012). Embodiment. In W. Hollway, H. Lucey, A. Phoenix, & G. Lewis (Eds), *Critical readings in social psychology*. Milton Keynes: The Open University.

Fobair, P., & Spiegel, D. (2009). Concerns about sexuality after breast cancer. *The Cancer Journal (Sudbury, Mass.)*, 15(1), 19-26.

Fobair, P., & Spiegel, D. (2009). Concerns about sexuality after breast cancer. *Cancer Journal*, Sudbury, MA., 15(1) 19-26.

Fobair, P., Stewart, S. L., Chang, S., D'Onofrio, C., Banks, P. J., & Bloom, J. R. (2006). Body image and sexual problems in young women with breast cancer. *Psycho-Oncology, 15,* 579–594.

Frank, A. W. (2013). *The wounded storyteller: Body, illness, and ethics.* (2nd edition). Chicago and London: The University of Chicago Press.

Frost, N. (2011). *Qualitative research methods in psychology: Combining core approaches.* Berkshire: Open University Press.

Frumovitz, M., Sun, C. C., Schover, L. R., Munsell, M. F., Jhingran, A., Wharton, J. T., ... Bodurka, D. C. (2005). Quality of life and sexual functioning in cervical cancer survivors. *Journal of Clinical Oncology, 23*(30), 7428-7436.

Ganz, P. A., & Greendale, G. A. (2007). Female sexual desire – beyond testosterone. *Journal of the National Cancer Institute*, *99*(9), 659-661.

Ganz, P. A., Rowland, J. H., Desmond, K., Meyerowitz, B. E., & Wyatt, G. E. (1998). Life after breast cancer: Understanding women's health-related quality of life and sexual functioning. *Journal of Clinical Oncology, 16,* 501–514.

Ganz, P., Desmond, K., Belin, T., Meyerowitz, B., & Rowland, J. (1999). Predictors of sexual health in women after a breast cancer diagnosis. *Journal of Clinical Oncology, 17*(8), 2371–2380.

Ghane, A., & Sweeny, K. (2013). Embodied health: A guiding perspective for research in health psychology. *Health Psychology Review*, *7*(sup1), S159-S184.

Gilbert, E, Ussher, J. M. and Perz, J. (2013) Embodying sexual subjectivity after cancer: A qualitative study of people with cancer and intimate partners. *Psychology & Health, 28*(6), 603–619.

Giorgi, A. (1997). The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. *Journal of Phenomenological Psychology*, *28*(2), 235.

Giorgi, A. (2011). IPA and science: A response to Jonathan Smith. *Journal of Phenomenological Psychology*, *42*(2), 195–216.

Glenberg, A. M. (2010). Embodiment as a unifying perspective for psychology. *Wiley Interdisciplinary Reviews: Cognitive Sciences*, *1*(4), 586-596.

Gopie, J. P., ter Kuile, M. M., Timman, R., Mureau, M. A. M., & Tibben, A. (2014). Impact of delayed implant and DIEP flap breast reconstruction on body image and sexual satisfaction: A prospective follow-up study. *Psycho-Oncology 23*, 100–107.

Graham, C. A., Boynton, P. M., & Gould, K. (2017). Women's sexual desire: Challenging narratives of "Dysfunction". *European Psychologist*, *22*(1), 27-38.

Grunfeld, E. A., Drudge-Coates, L., Rixon, L., Eaton, E., & Cooper, A. F. (2013). "The only way I know how to live is to work": A qualitative study of work following treatment for prostate cancer. *Health Psychology: Official Journal of the Division of Health Psychology*, American Psychological Association, *32*(1), 75.

Harcourt, D., & Rumsey, N. (2001). Psychological aspects of breast reconstruction: A review of the literature. *Journal of Advanced Nursing,* 35(4), 477-487.

Health and Care Professions Council (HCPC) (2018). Standards of proficiency for Practitioners Psychologists. Retrieved on the 8th June 2018 from: http://www.hcpc-uk.org/assets/documents/10002963SOP_Practitioner_psychologists.pdf

Hecht, M. L. (1993). 2002—a research odyssey: Toward the development of a communication theory of identity. *Communication Monographs*, *60*(1), 76-82.

Henson, H. K. (2002). Breast cancer and sexuality. *Sexuality and Disability, 20*(4), 261-275.

Henson, H. K. (2002). Breast cancer and sexuality. *Sexuality and Disability, 20*(4), 261-275.

Hollway, W., Lucey, H., Phoenix, A., & Lewis, G. (2012). *Social biology matters*. Milton Keynes: Open University Press. Second edition.

Hordern, A. (2000). Intimacy and sexuality for the woman with breast cancer. *Cancer Nursing*, *23*(3), 230-236.

Hungr, C., Sanchez-Varela, V., & Bober, S. L. (2017). Self-image and sexuality issues among young women with breast cancer: Practical recommendations. *Revista De Investigacion Clinica; Organo Del Hospital De Enfermedades De La Nutricion, 69*(2), 114.

Huppert, F. A. (2009). Psychological well-being: Evidence regarding its causes and consequences. *Applied Psychology: Health and Well-being, 1*(2), 137-164.

Keitel, M. A., & Kopala, M. (2000). *Counseling women with breast cancer: A guide for professionals.* Thousand Oaks, CA and London: SAGE.

Kiebert, G. M., de Haes, J. C., & van de Velde, C. J. (1991). The impact of breast-conserving treatment and mastectomy on the quality of life of early-stage breast cancer patients: A review. *Journal of Clinical Oncology, 9*(6), 1059-1070.

Kim, J., Han, J. Y., Shaw, B., McTavish, F. & Gustafson, D. (2010). The roles of social support and coping strategies in predicting breast cancer patients' emotional wellbeing: testing mediation and moderation models. Journal of Health Psychology, *15*(4): 543-52.

Kinamore, C. (2008). Assessing and supporting body image and sexual concerns for young women with breast cancer: A literature review. *Journal of Radiotherapy in Practice, 7*(3), 159-171.

Knobf, M. T. (2002). Carrying on: The experience of premature menopause in women with early stage breast cancer. *Nursing Research*, *51*, 9-17.

Krebs, L. (2006). What should I say? Talking with patients about sexuality issues. *Clinical Journal of Oncology Nursing*, *10*(3), 313-315.

Krychman, M. and Millheiser, L. S. (2013). Sexual health issues in women with cancer. *Journal of Sexual Medicine*, *10*(1), 5-15.

Kübler-Ross, E., & Kessler, D. (2005). *On grief and grieving*: *Finding the meaning of grief through the five stages of loss*. London: Simon & Schuster.

Kundrat, A. L., & Nussbaum, J. F. (2003). The impact of invisible illness on identity and contextual age across the life span. *Health Communication, 15*(3), 331-347.

Kvale, K., & Bondevik, M. (2008). What is important for patient centred care? A qualitative study about the perceptions of patients with cancer. *Scandinavian Journal of Caring Sciences*, *22*(4), 582-589.

Kvale, S., & Brinkmann, S. (2015). *InterViews: Learning the craft of qualitative research interviewing (3rd edn.).* Los Angeles: Sage Publications.

Langdridge, D. (2007). *Phenomenological psychology: Theory, research and method*. Harlow: Pearson Prentice Hall.

Langellier, K. M., & Sullivan, C. F. (1998). Breast talk in breast cancer narratives. *Qualitative Health Research*, 8(1), 76-94.

Larkin, M., Loaring, J. M., & Shaw, R. (2015). Renegotiating sexual intimacy in the context of altered embodiment: The experiences of women with breast cancer and their male partners following mastectomy and reconstruction. *Health Psychology*, *34*(4), 426-436.

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, *3*(2), 102–120.

Lavie, M., & Willig, C. (2005). 'I don't feel like melting butter': An interpretative phenomenological analysis of the experience of 'inorgasmia'. *Psychology and Health, 20*, 115–128.

Lehmiller, J. J. (2014). *The psychology of human sexuality*. Chichester, West Sussex, UK: Wiley Blackwell.

Lehmiller, J. J. (2017). Controversial issues in human sexuality research: The state of the science. *European Psychologist, 22*(1), 1-4.

Liu, C. J., Hsiung, P. H., Chang, K. J., Liu, Y. F., Wang, K. C., Hsiao, F. H., … Chan, C. L. W (2008). A study on the efficacy of body–mind–spirit group therapy for patients with breast cancer. *Journal of Clinical Nursing*; *17*, 2539–2549.

Loaring, J. M., Larkin, M., Shaw, R., & Flowers, P. (2015). Renegotiating sexual intimacy in the context of altered embodiment: The experiences of women with breast cancer and their male partners following mastectomy and reconstruction. *Health Psychology: Official Journal of the Division of Health Psychology*, American Psychological Association, 34(4), 426-436.

Maclaren, K. (2014). Touching matters: Embodiments of intimacy. *Emotion Space and Society, 13*, 95-102.

Male, D., Fergus, K. D., & Cullen, K. (2015). Sexual identity after breast cancer: Sexuality, body image, and relationship repercussions. *Current Opinion in Supportive and Palliative Care*, *10*(1), 66-74.

Marcus, A. C., Garret, K. M., Cella, D., Wenzel, L., Brady, M. J., Fairclough, D., Pate-Willig, M., Barne, D., Emsbo, S. P., Klushman, B. C., Crane, L., Sedlacek, S., and Flynn, P. J. (2010). Can telephone counselling post-treatment improve psychosicial outcomes among early stage breast cancer survivors? *Psychooncology, 19*(9): 923–932.

Marshall C., & Kiemle, G. (2005). Breast reconstruction following cancer: Its impact on patients' and partners' sexual functioning. *Sexual and Relationship Therapy*, *20*(2), 155-177.

Marshall, C. E., Lengyel, C. O., & Menec, V. H. (2014). Body image and body work among older women: A review. *Ethnicity and Inequalities in Health and Social Care*, *7*(4), 198-210.

Martin, S. C. (2016). The experience and communicative management of identity threats among people with Parkinson's Disease: Implications for health communication theory and practice. *Communication Monographs, 83*(3), 303-325.

Matthews, H., Grunfeld, E. A., & Turner, A. (2017). The efficacy of interventions to improve psychosocial outcomes following surgical treatment for breast cancer: A systematic review and meta-analysis. *Psycho-oncology*, *26*(5), 593-607.

McKee, A. L., & Schover, L. R. (2001). Sexuality rehabilitation. *Cancer, 92*(4), 1008-1012.

Merleau-Ponty, M. (1962). *Phenomenology of perception* (C. Smith, Trans.). London: Routledge.
Merleau-Ponty, M. (1968). *The visible and the invisible* (A. Lingis, Trans.). Evanston, IL: Northwestern University Press. (Original work published 1964).

Miller, J. A. (2000). The fear of the body in psychotherapy. *Psychodynamic Counselling*, *6*, 437-448.

Moorey, S. (2013). I know they are distressed. What do I do now? *Psycho-Oncology, 22*(9), 1946-1952.

Moustakas, C. (1994). *Phenomenological research methods*. London: Sage.

National Health Service (NHS) (2018). Treatment: Breast cancer in women. Retrieved on the 18th November 2018 from: https://www.nhs.uk/conditions/breast-cancer/treatment/

National Institute for Health and Care Excellence (NICE) (2018). Breast cancer: NICE Pathways and NICE Guidelines: Retrieved on the 18th November 2018 from: https://www.nice.org.uk/guidance/conditions-and-diseases/cancer/breast-cancer#panel-pathways

National Institute for Health and Care Excellence (NICE) (2004). Guidelines for treatment of breast cancer. Advanced breast cancer: diagnosis and treatment. Retrieved on 8th June 2018 from: https://www.nice.org.uk/Guidance/CG81

National Institute for Health and Care Excellence (NICE) (2009). Advanced breast cancer/ diagnosis and treatment. Retrieved on the 8th June 2018 from: https://www.nice.org.uk/guidance/cg81/chapter/Recommendations#systemic-disease-modifying-therapy

Oris, L., Luyckx, K., Rassart, J., Goubert, L., Goossens, E., Apers, S., ... Moons, P. (2018). Illness identity in adults with a chronic illness. *Journal of Clinical Psychology in Medical Settings.* Retrieved from https://doi/10.1007/s10880-018-9552-0

Parton, C. M., Ussher, J. M., & Perz, J. (2015). Women's construction of embodiment and the abject sexual body after cancer. *Qualitative Health Research*, *26*(4), 490.

Perz, J., Ussher, J. M., & Gilbert, E. (2013). Constructions of sex and intimacy after cancer: Q methodology study of people with cancer, their partners, and health professionals. *BMC Cancer*, *13*, 270. Retrieved from http://www.biomedcentral.com/1471-2407/13/270

Perz, J., Ussher, J. M., Gilbert, E., & The Australian Cancer and Sexuality Study Team (2014). Feeling well and talking about sex: Psycho-social predictors of sexual functioning after cancer. *BMC Cancer*, *14*(1), 228.

Pillai-Friedman, S., & Ashline, J. L. (2014). Women, breast cancer survivorship, sexual losses, and disenfranchised grief – a treatment model for clinicians. *Sexual and Relationship Therapy*, *29*(4), 436-453.

Pinto, A. C. (2013). Sexuality and breast cancer: Prime time for young patients. *J Thorac*

Dis, 5(S1), S81-S86.

Ponterotto, J. G. (2005). Qualitative research in counselling psychology: A primer on research paradigms and philosophy of science. *Journal of Counselling Psychology, 52*(2), 126–136.

Przezdziecki, A., Sherman, K. A., Baillie, A., Taylor, A., Foley, E., & Stalgis-Bilinski, K. (2013). My changed body: Breast cancer, body image, distress and self-compassion. *Psycho-oncology*, *22*(8), 1872-1879.

Rafalin, D. (2010). Counselling psychology and research: Revisiting the relationship in the light of our 'mission'. In M. Milton (Ed.), *Therapy and beyond: Counselling psychology contributions to therapeutic and social issues* (pp. 41-55). Oxford: Wiley-Blackwell.

Raggio, G. A., Butryn, M. L., Arigo, D., Mikorski, R., & Palmer, S. C. (2014). Prevalence and correlates of sexual morbidity in long-term breast cancer survivors. *Psychology & Health*, *29*(6), 632–650.

Reese, J. B., Bober, S. L., & Daly, M. B. (2017). Talking about women's sexual health after cancer: Why is it so hard to move the needle?: Sexual health for women with cancer. *Cancer, 123*(24), 4757-4763.

Reese, J. B., Porter, L., Bober, S. L., & Lapore, S. J. (2017). Effective patient provider communication about sexual concerns in breast cancer: A qualitative study. *Support Care Cancer*, *25*, 3199–3207.

Reich, M., Lesur, A., & Perdrizet-Chevallier, C. (2008). Depression, quality of life and breast cancer: A review of the literature. *Breast Cancer Res Treat*, *110*, 9–17.

Rodrigues, A. C., Teixeira, R., Teixeira, T., Conde, S., Soares, P., & Torgal, I. (2012). Impact of pelvic radiotherapy on female sexuality. *Arch Gynecology and Obstetrics, 285*(2), 505-514.

Rodríguez-Prat, A., Monforte-Royo, C., Porta-Sales, J., Escribano, J., & Balaguer, A. (2016). Patient perspectives of dignity, autonomy and control at the end of life: Systematic review and meta-ethnography. *PLoS One, 24*, 11(3), 1-18.

Rogers, C. R. (1975). Empathy: An unappreciated way of being. *The Counselling Psychologist*, 5, 2-10.

Rosen, R., Brown, C., Heiman, J., Leiblum, S., Meston, C., Shabsigh, R., … D'Agostino, R. (2000). The female sexual function index (FSFI): A multidimensional self-report instrument for the assessment of female sexual function. *Journal of Sex & Marital Therapy*, *26*, 191–208.

Rowland, J. H., Desmond, K. A., Meyerowitz, B. E., Belin, T. R., Wyatt, G. E., & Ganz, P. A. (2000). Role of breast reconstructive surgery in physical and emotional outcomes among breast cancer survivors. *Journal of the National Cancer Institute, 92*(17), 1422-1429.

Safarinejad, M. R., Shafiei, N., & Safarinejad, S. (2013). Quality of life and sexual functioning in young women with early-stage breast cancer 1 year after lumpectomy. *Psycho-Oncology*, *22*, 1242–1248.

Schover L. R., Fife, M., & Gershenson, D. M. (1989). Sexual dysfunction and treatment for early stage cervical cancer. *Cancer, 63*(1), 204-212.

Schover, L. R. (1991). The impact of breast cancer on sexuality, body image and intimate relationships. *Cancer Journal for Clinicians, 41,* 112–120.

Schover, L. R. (2005). Motivation for parenthood after cancer: A review. *Journal of the National Cancer Institute Monographs, 34*, 2-4.

Schover, L. R. (2008). Premature ovarian failure and its consequences: Vasomotor symptoms, sexuality, and fertility. *Journal of Clinical Oncology*, *26*(5), 753-758.

Schover, L. R., Yetman, R. J., Tuason, L. J., Meisler, R. N., Esselstyn, C. B., Hermann, R. E., ... Dowden, R. V. (1995). Partial mastectomy and breast reconstruction. *Cancer*, *75*(1), 54-64.

Schover, L. R., Yuan, Y., Fellman, B. M., Odensky, E., Lewis, P. E., & Martinetti, P. (2013). Efficacy trial of an internet-based intervention for cancer-related female sexual dysfunction. *J Natl Compr Canc Netw, 11*(11), 1389-1397.

Schover, L. R., Yuan, Y., Fellman, B. M., Odensky, E., Lewis, P. E., & Martinetti, P. (2013). Efficacy trial of an internet-based intervention for cancer-related female sexual dysfunction. *J Natl Compr Canc Netw, 11*(11), 1389-1397.

Seligman, M. (2002). *Authentic happiness*. New York: Free Press.

Seymour, W. (2007). Exhuming the body: Revisiting the role of the visible body in ethnographic research. *Qualitative Health Research, 17*(9), 1188–1197.

Shifren, J. L., Johannes, C. B., Monz, B. U., Russo, P. A., Bennett, L., & Rosen, R. (2009). Help-seeking behaviour of women with self-reported distressing sexual problems. *Journal of Women's Health, 18*(4), 461-468.

Siegel, R., Naishadham, D., & Jemal, A. (2013). Cancer statistics, 2013. *CA: A Cancer Journal for Clinicians, 63*(1), 11-30.

Slatman, J. (2014). Multiple dimensions of embodiment in medical practices. *Medicine Health Care and Philosophy, 17*(4), 549-557.

Smith, C. (1964). The notion of object in the phenomenology of Merleau-Ponty. *Philosophy, 39*(148), 110–119.

Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology & Health, 11*(2), 261–271.

Smith, J. A. (1999). Identity development during the transition to motherhood: An interpretative phenomenological analysis. *Journal of Reproductive and Infant Psychology, 17*(3), 281–299.

Smith, J. A. (2010). Interpretative phenomenological analysis: A reply to Amedeo Giorgi. *Existential Analysis, 21*(2), 186.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis:*

Theory, method and research. London & Los Angeles: SAGE.

Smith, J.A. and Osborn, M. (2015). Interpretative phenomenological analysis. In J.A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods (3rd ed.)* (pp. 53-80). London: Sage Publications.

Soothill, K., Morris, S. M., Harman, J., Francis, B., Thomas, C., & McIllmurray, M. B. (2001). The significant unmet needs of cancer patients: Probing psychosocial concerns. *Support Care Cancer*, *9*, 597–605.

Spencer, L., Ritchie, J., & O'Connor, W. (2003) Analysis: Practices, principles and processes. In J. Ritchie & J. Lewis (eds.), *Qualitative research practice: A guide for social scientist students and researchers.* (pp. 199-218). London: Sage.

Starks, H., & Trinidad, S. B. (2007). Choose your method: A comparison of phenomenology, Discourse Analysis, and Grounded Theory. *Qualitative Health Research*, *17* Number 10, 1372–1380.

Stead, M. L., Brown, J. M., Fallowfield, L., & Selby, P. (2003). Lack of communication between healthcare professionals and women with ovarian cancer about sexual issues. *British Journal of Cancer*, *88*(5), 666-671.

Svenaeus, F., Institutionen för kultur och kommunikation, Centrum för praktisk kunskap, & Södertörns högskola. (2011). Illness as unhomelike being-in-the-world: Heidegger and the phenomenology of medicine. *Medicine, Health Care and Philosophy*, *14*(3), 333-343.

Tierney, K. D. (2008). Sexuality: A qualitative of life issue for cancer survivors. *Seminars in Oncology Nursing*, *24(2),* 71-79.

Torresan, M. M., Garrino, L., Borraccino, A., Macchi, G., De Luca, A., & Dimonte, V. (2015). Adherence to treatment in patient with severe cancer pain: A qualitative enquiry through illness narratives. *European Journal of Oncology Nursing,* 19, 397-404.

Van der Kolk, B. A. (2014). *The body keeps the score: Brain, mind, and body in the healing of trauma* [Kindle edition]. New York: Viking.

Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy.* Albany, NY: SUNY Press.

Van Manen, M. (2014). *Phenomenology of practice: Meaning-giving methods in phenomenological research and writing.* Walnut Creek, CA: Left Coast Press.

Wertz, F. J. (2005). Phenomenological research methods for counseling psychology. *Journal of Counseling Psychology, 52*(2), 167–177.

White, C. A. & Hood. C. (2014). In Cash, T. F. & Smolak, L. (Eds.), *Body image issues in oncology* in *Body image: A handbook of science, practice, and prevention.* New York: Guilford Publications, 333-340.

White, I. D., Allan, H., & Faithfull, S. (2011). Assessment of treatment-induced female sexual morbidity in oncology: Is this a part of routine medical follow-up after radical pelvic radiotherapy? *British Journal of Cancer*, *105*(7), 903-910.

White, I., & Butcher, J. (2015). Call for Contributions. Special Issue: The sexual & relationship consequences of cancer and its treatments. *Sexual and Relationship Therapy*, *30*(2), 301–302.

Wilkinson, S., & Kitzinger, C. (1993). Whose breast is it anyway? *Women's Studies International Forum, 16*(3), 229-238.

Willig, C. (2011). Cancer diagnosis as discursive capture: Phenomenological repercussions of being positioned within dominant constructions of cancer. *Social Science & Medicine, 73*(6), 897-903.

Willig, C. (2013). *Introducing qualitative research in psychology* (3rd edition). Maidenhead: McGraw-Hill Education.

Willig, C., Stainton Rogers, W., & SAGE Research Methods Core. (2017). *The SAGE handbook of qualitative research in psychology* (2nd; Second; ed.). London; Thousand Oaks, California; SAGE Publications, pp. 278.

Wilmoth, M. C. (1998). Sexuality. In Burke, C. (Ed.), *Psychosocial dimensions of oncology nursing care.* Pittsburgh (PA): Oncology Nursing Press, p.102-127.

Wilmoth, M. C. (2006). Life after cancer: What does sexuality have to do with it? *Oncology Nursing Forum*, *33*(5), 905-910.

World Cancer Research Fund (WCRF) (2018). Data on breast cancer statistics. Retrieved on the 10th June 2018 from: https://www.wcrf.org/int/cancer-facts-figures/data-specific-cancers/breast-cancer-statistics

World Health Organisation (WHO) (1946). Preamble to the Constitution of the World Health. Retrieved on the 18th July 2018 from: *www.who.int/library/historical/access/who/index.en.shtml*.

World Health Organisation (WHO) (2014). Promoting Mental Health Concepts Emerging Evidence and Practice. Retrieved on the 18th July 2018 from: http://www.who.int/features/factfiles/mental_health/en/.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health, 15*(2), 215–228.

7. APPENDICES

7.1. Recruitment Advert

CITY UNIVERSITY LONDON

Department of Psychology
City University London

PARTICIPANTS NEEDED:

RESEARCH IN '*FEMALE SEXUALITY & FEMININITY DURING BREAST CANCER REHABILITATION*'

We are looking for volunteers to take part in a study on Female Sexuality During Breast Cancer Rehabilitation.

You would be asked to:

Attend an individual confidential brief interview.

Your participation would involve one meeting,
of which approximately *60* minutes.

For more information about this study, or to take part,
please contact:
Ana Silvestri

Email: ███████████████ or ████████████

This study has been reviewed by, and received ethics clearance through the Research Ethics Committee, City University London [PSYETH (P/F) 15/16 19].

If you would like to complain about any aspect of the study, please contact the Secretary to the University's Senate Research Ethics Committee on ███████████ or via email:

████████████████████

7.2. Phone triage: Pre-interview risk assessment

1. How long ago did you finish your breast cancer treatment?
2. How do you feel emotionally talking about that experience now that is finished?
3. How are you doing at the moment?
4. Have you suffered from anxiety or depression since your breast cancer treatment finished?
5. Are you engaged with any psychological services for emotional support?

CITY UNIVERSITY
LONDON

A Holistic Approach to Care for Women Struggling after Mastectomy: An Interpretative Phenomenological Analysis

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of this study?

The research is part of a counselling psychology doctoral degree programme and it aims to investigate the experience of sexuality and femininity in women breast cancer patients through a brief, private and individual interview. I intend to explore personal accounts in order to gain a better understanding of how women negotiate the physical and psychological changes.

You will be required to participate on a brief, semi-structured interview related to the experience of sexuality after breast cancer. This interview will last between 60-90 minutes, depending on how much you would like to share. Your participation will be concluded once the interview is finished and no further involvement will be required.

The research method being used in this study is Interpretative Phenomenological Analysis (IPA). IPA is a qualitative research method, commonly used in the field of counselling psychology. It focuses on the in-depth lived experiences of each participant within a given context, in order to make sense of a commonly shared experience. The event being studied in this instance is the experience of women's sexuality following breast cancer treatment.

Why have I been invited?

I am interviewing 8-10 participants in total for this study. The data collected will be kept confidential and it will be securely locked away in an encrypted file. Data published in the research will be made absolutely anonymous (name, age and any identifiable personal details). You have been invited due to your experience of breast cancer. Ethics Committee has reviewed this proposal before research proceeding. It is common practice to have studies involving human participants reviewed by an Ethics Committee.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. Taking part in this study is entirely voluntary. Your participation is **not** compulsory. In case you decide to participate on this research project, you can withdraw at any stage of the project without being penalised or disadvantaged in any way.

This research will take place at City University offices in central London. No financial rewards will be provided.

What do I have to do?

I expect you to sit with me in a quiet office and allow me to audio record our conversation regarding your experience of sexuality and femininity after breast cancer. I will be asking an average of ten exploratory open-ended questions about your experience and you can share with me as much or as little as you wish to.

What are the possible disadvantages and risks of taking part?

This research does not offer any risks for your health. However, we will be discussing potentially sensitive topics relating to your sexuality, femininity, and your breast cancer experience.

What are the possible benefits of taking part?

The benefits this research could present are for the wider community, clinicians and anyone interested on the topic of sexuality and femininity after breast cancer. Medical staff may benefit from the information this study will produce and the data gathered can

help with the development of services and hopefully encourage the inclusion of counselling psychologists on the multidisciplinary teams in hospitals and clinics.

What will happen when the research study stops?

Once the study is completed, I am required to keep the record of your data for the period of five years. After that period is finished I will be destroying the information.

Will my taking part in the study be kept confidential?

The only people who will have access to the information shared will be my allocated academic supervisor and myself. I will be recording our interview on my computer through a computer programme. A digital recorder will also be used as a backup device. As soon as the interview is finished I will download the digital data into my laptop and securely store it into an encrypted file. You personal information will not be used in the future. Our interview is confidential. The only situations in which confidentiality would be breeched would be if you mentioned serious criminal activity.

What will happen to the results of the research study?

It is likely that this study will be published in future healthcare publications as well as the current counselling psychology doctoral thesis. Confidentiality will be maintained throughout the process.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team (███████████████). If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: '*The Experience of Female Sexuality During Breast Cancer Rehabilitation: An Interpretative Phenomenological Analysis.*'

You could also write to the Secretary at:
Anna Ramberg
Secretary to Senate Research Ethics Committee
Research Office, E214

City University London
Northampton Square
London
EC1V 0HB
Email: ███████████████████

City University London holds insurance policies, which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

This study has been approved by City University London Psychology Research Ethics Committee, PSYETH (P/F) 15/16 19.

Further information and contact details
Should you wish to contact someone regarding any enquiries about the research the main point of contact is: ███████████████ or, alternatively ███████████████

Thank you for taking the time to read this information sheet.

CITY UNIVERSITY LONDON

A Holistic Approach to Care for Women Struggling after Mastectomy:

An Interpretative Phenomenological Analysis

Ethics approval code: PSYETH (P/F) 15/16 19

Please initial box

1.	I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records. I understand this will involve: • being interviewed by the researcher • allowing the interview to be digitally recorded	
2.	This information will be held and processed for the following purpose(s): '***how do female breast cancer patients experience and make sense of their sexuality and femininity during breast cancer rehabilitation?'*** I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.	
3.	I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can	

	withdraw at any stage of the project without being penalized or disadvantaged in any way.	
4.	I agree to City University London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.	
5.	I agree to take part in the above study.	

_____   _____ _____

Name of Participant   Signature   Date

_____   _____ _____

Name of Researcher   Signature   Date

(When completed, 1 copy for participant; 1 copy for researcher file)

Note to researcher: to ensure anonymity, consent forms should NOT include participant numbers and should be stored separately from data.

CITY UNIVERSITY LONDON

A Holistic Approach to Care for Women Struggling after Mastectomy:
An Interpretative Phenomenological Analysis

<u>Main Questions</u>

1. This study is about the impact of breast cancer and treatment and surgery on women in relation to their femininity and sexuality. Could you tell me how did you feel in relation to this when you were first diagnosed with breast cancer?
2. What was it like to take the first step into treatment? (Emotional responses).
3. Did you have a choice over treatment? What would you say was the main reason for choosing that particular treatment? Can you please elaborate on that?
4. Can you describe me your experience of bodily (physical) changes throughout the cancer treatment?
5. Can you tell me more about the changes you have been through emotionally (individually/relationships)?
6. Can you tell me about how did you cope with sexual changes (emotionally and physically) that have arisen during cancer treatment?
7. Can you describe me the feelings around re-adjusting to your body after surgery (scaring, removed parts, reconstruction) and the ways in which you have been dealing with its changes?
8. In the context of your femininity, during this recovery phase, how do you experience your sexuality (physically and emotionally + individually)?
9. What does it mean for you to be recovering sexually from breast cancer treatment? Can you elaborate further please?
10. How do you feel now (physically and emotionally) in the context of your sexuality during this recovery process? Can you please elaborate further?
11. Why did you choose to take part in this study? And, how do you feel now after our interview?

<u>Sub-questions</u>

12. Can you tell me your story? Talk me through the illness from when you first found out until now.

13. Tell me how that affected/impacted your sexuality/body?
14. How do you feel about that now during the rehabilitation phase? How does that relate to your sexuality?

CITY UNIVERSITY LONDON

A Holistic Approach to Care for Women Struggling after Mastectomy:

An Interpretative Phenomenological Analysis

Thank you for taking part in this study. Now that it's finished, we'd like to tell you a bit more about it. The proposed research intends to contribute to a greater understanding of female's individual perspectives on sexuality following cancer treatment and how that affects their overall wellbeing and quality of life.

The proposed study aims to explore and enquire into the subjective experience of women patients and their accounts of their sexuality within the context of breast cancer treatment and recovery process. The study will particularly focus on the embodied relational and sexual experiences of patients, and the ways in which self-perception and the perception of others (partners) are taken into account when negotiating physical and emotional changes. If you have any problems, concerns or feel the need to talk to someone about your feelings please contact your GP. Alternatively, please see below a list of services available:

> **British Psychological Society (BPS)** (full price of reduced fee schemes)**:**
> http://www.bps.org.uk/psychology-public/find-psychologist/find-psychologist.
> **Mind** *(free of charge)***:**
> http://www.mind.org.uk/information-support/local-minds/.
> **MacMillan:**
> http://www.macmillan.org.uk/information-and-support/coping/your-emotions/who-can-help/help-from-your-healthcare-team.html.

We hope you found the study interesting. If you have any other questions please do not hesitate to contact us at the following:

Researcher: ▮▮▮▮▮▮▮▮▮▮▮▮ (If you have issues with the research please contact alternatively - ▮▮▮▮▮▮▮▮▮▮▮▮)

Ethics approval code: PSYETH (P/F) 15/16 19

7.7. Transcript Sample

Line #	Original Transcript	Analysis Notes ==Descriptive== ==Linguistic== Conceptual	Emergent Codes (Sub-themes)	Major themes
50	ABBI: I didn't really have time to think too much because it was sort of on it, on it [phone rings] and then that's it literally how we progressed you know?	She seems to have chosen to disconnect from her emotions and focused on the practical side of improving her health. Again separating the physical and psychological processes during recovery.	*Sudden (SHOCK)* "*I didn't really have time to think too much because it was sort of on it, on it…*"	**Ill Self**
51	Researcher: Uhm, yeah.			
52	ABBI: Just a continuous, [phone rings] yeah, just get through it really [phone rings].	She gets into a practical mode seemly as a survival technique to 'push through' into recovery.	*Kicked into survival (WARRIOR)* "*Just a continuous, [phone rings] yeah, just get through it really.*"	**Coping Self**
53	Researcher: Um			
54	ABBI: I found I think, this time, the second time, more intrusive and more difficult in the way that I feel and perceive myself in terms of… you know…	Self-concept and sexuality seem to suffer with the invasive cancer treatment but she cannot quite express what is the difference.	*Intrusive (PAIN – PSYCH & PHYSICAL)* "*…the second time, more intrusive and more difficult in the way that I feel and perceive myself in terms of… you know…*"	**Ill Self**
55	Researcher: Your sexuality? [Spoke over each other]			

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56	ABBI: Yeah! This one seems harder to deal with…		*Intrusive (PAIN-PSYCH & PHYSICAL)* Yeah! This one seems harder to deal with…	**Ill Self**
57	Researcher: Uhm, I wonder what is different…			
58	ABBI: [Sigh] Erm, the second time, so I haven't been, so I wasn't well last year and this I was just very unlucky. I had a rogue cell that just crept across the upper side of my collar bone, so that has affected the lymph nodes in my neck and again just very unlucky. This hasn't been as traumatic in terms of the treatment as it has been a constant 18 weeks of chemo, every Tuesday and that some side effects nowhere near as bad as before…	Second breast cancer occurrence is described as having impacted her psychologically (intimacy & sexuality) more than physically. *"The language of despair" (Susan Sontag)* *"I had a rogue cell that just crept across the upper side of my collar bone, so that has affected the lymph nodes in my neck and again just very unlucky."* I feel that she is uncertain about sharing her intimacy with me. I am not sure whether she is generally uncomfortable in doing that or whether it was the case of not knowing me well enough to expose her intimacy. She seems to feel more vulnerable in this second episode.	*Intrusive (PAIN - PHYSICAL)* *"Erm, the second time, so I haven't been, so I wasn't well last year and this I was just very unlucky. I had a rogue cell that just crept across the upper side of my collar bone, so that has affected the lymph nodes in my neck and again just very unlucky."* *Intrusive (PAIN - PSYCH)* *"This hasn't been as traumatic in terms of the treatment as it has been a constant 18 weeks of chemo, every Tuesday and that some side effects nowhere near as bad as before…"*	**Ill Self**
59	Researcher: Uhm…			

7.9. Emerging Themes Sample (Picture II)

The experience of femininity & sexuality during breast cancer recovery.

(IPA)

*Embodiment —— Illness: Mind/Body integration
*Self-concept —— Self-esteem/self-image
*Female sexuality —— self-to-self/self-to-other

The Vulnerable Self

(AKI)

* 'Surrendering the body exposing self/psychology?'

- Adaptation to new image — Gaze of others — Contrl 'Surrender'
- Being under the care of others felt like regressing — Contrl 'taking'
- Can't fall apart — Contrl 'taking' — Contrl 'taking'
- Cancer taking over — Contrl 'taking'
- Choice over reconstruction — Contrl 'taking'
- Do as I'm told — Contrl 'Surrender'
- Doctors don't invite talks about sexual change and coping! uncertainty
- Fear of rejection — uncertainty
- Felt less feminine — Gaze of others
- Invasive surgery (penetrating) — Contrl 'Surrender'
- Keeping tight control over emotional expression by contrl 'taking'
- Concealing pain (emotional + physical) — Contrl 'taking'
- Life on hold — uncertainty
- Little control — Contrl 'Surrender'
- Loosing masculine without hair — Gaze of others
- Missing out in life — uncertainty
- Missing parts — Gaze of others
- Mortality — uncertainty
- Not as attractive] Gaze of others
- Not as feminine
- Organising housing & finances — uncertainty
- Partner looking away] Gaze of others
- Pleasing partner
- Reconstructed from myself
- Reconstructed (less distressing)] Contrl 'taking'
- Special case — Gaze of others
- Surrendering power ——— Contrl 'Surrender'
- Taking control — Contrl 'taking'

INITIAL EXP.

BECOMING A PATIENT (Body/Mind intertwined)

'Preparing for hardship ahead'
'Shock'
'Slow steps into new identity'
'Cyborg'
'I'm a person in my own right'
'Change in roles'
'Holding to pain'
'Losing parts' (hair, skin, fluids...)
'Unexpected' - 'Sudden'
'Anger' - 'Sadness' - 'Upset' - 'Sorrow'; 'worries'
'Annoyance' - 'Anxiety' - 'Fear' -
'Pain' - 'Relief' - 'Self-blame'
'Menopause' (loss of libido)
'Abnormal body' - 'Body changes'
'No sex'
'Treating the body but not the mind'

Exposed
Physically /
Emotionally

'Feeling unfeminine'
'Reconstruction'
'Not offering anything in exchange for loss'
'Pressured by how breasts are portrayed in society' 'overexy bra'
'Turn up live cattle'
'Adapting to new image'
'Self-conscious' (masks)'
'Replaced by the younger woman with two breasts'
'Missing regular professional care' 'reassurance from 'Barbie boobs' gardener'
'Body Asymmetry'
'Uncertainty' (how will life unfold?)
'Control' - illness taking over'

Pick Up Pieces
Recovering wellbeing

'Warrior' - Business as usual'
'Self-preservation'
'Connect' (to others / to self (sharing experiences) stronger back)
'Mother did not have choice over reconstruction'
'Stoic'
'Sparing family from pain'
'Not over fussing' 'Reclaiming wellness'
'Deeper connections' 'Placing time for sex'
'Celebrating femininity'
'Sexually alive' 'Exploring new looks'
'Body therapy' 'holistic treatments'
'Wonder of coping'
'waking up fat'
'Humour'
'Lacking psych support at clinic'

Ill Self	Vulnerable Self	Coping Self
Shock	Control	Warrior
Pain	Uncertainty	Comparing losses
Body Changes	Other's gaze	Recovering

7.12. **Table of Themes (Table III)**

MAJOR THEMES	Ill Self	Line number	Vulnerable Self	Line number	Coping Self	Line number
SUB-THEMES	*'Shock'* *Pain* *'Body changes'*		*'Control'* *'Uncertainty'* *'Other's Gaze'*		*'Warrior'* *'Comparing losses'* *'Recovering'*	
EMERGENT THEMES	Anger	225	Adapting to new image	80 259	Cancer cells are gone	179
	Becoming a patient	139 193	Below the surface	127	Comparing losses	317
	Change in roles	211	Cancer taking over	159 161	Connecting	271 277
	Chemo crotch	38 295	Control (taking/surrendering)	135 137 157 201 203 213 217 225 227	Group meeting	38
	Fear	8 169 225	Feeling unfeminine (Gendered)	68 76 84 119	Hopes for the future	319 321 323 325
	Grief	313	Missing out in life – no longer belonging	225	Humour	299 301
	Intimacy issues	62 72 90 94 261 267	Mortality	199 207 315 225 229	Keep up façade	241
	Intrusive (sexuality threatened)	54 58 60 72	Preparing for the worse	201 203	Kicked into survival	22 52 187 201

Losing parts (hair/ breast/ fluids / skin)	32 34 143 149	Partner looking away	82 117 251 257 261	Living in the present "for the here and now"	309 319
Loss of libido	38 40 100 108	Pleasing partner (gendered)	90 96	Moving on	305
Managing self-image	26 64 66 169			Network of support	22 24 179 195
Menopause	102 104			Not over fussing (Gendered)	185
Moulding to pain	36 241 245			Not the worse that happened	181 185
Pain (Psych & Physical)	311 313 169 175 241			Old grieve becomes accessible	185 189 315
Partner scared of hurting me during sex	42			Projecting wellness (positive portrait/gendered)	177 241 243
Reconstructed Self	143 151 153 167 171 247 283 285			Readjusting to body	285
Sadness	225 311			Sparing family from pain (gendered)	241 309
Scarring and wounds	141 145 169 285			Stoic (endure pain without complaining or showing emotions – gender role)	20 78 179 193 197
Selfish illness	193			Warrior	197 209 253 307 309 333
Shock	4 18				
Sudden	50				

		225				
	Suspicious	12 14				
	Unexpected	4 18 309				
	Weight Gain (steroids)	141				
	Weight loss (liposuction)	141 287				

Table of Themes with Participant's Quotes (Table IV)

Master Themes	Sub-themes	PARTICIPANT'S QUOTES NUMBERS							
		Abbi	Barbara	Carol	Deanne	Elena	Fiona	Gabi	Heather
III Self									
	Shock	4,12, 14, 18, 50, 215, 225, 309	2, 4, 12, 16, 20, 24, 26, 110, 135, 145, 375, 379	4, 46, 143, 173, 175,	14	104, 153, 201, 317, 341, 361, 363	34, 36, 38, 40, 42, 44, 46, 48, 54, 62, 66, 68	82, 84	54, 64, 66, 68, 70, 72, 100, 102, 104, 111, 119, 121, 123, 125, 127, 133, 205, 207,
	Pain	8, 36, 42, 43, 54, 58, 60, 139, 169, 175, 193, 225, 241, 245, 311, 313, 317	26, 28, 34, 74, 76, 203, 231, 239, 319, 345, 347, 351, 353, 355, 357, 359	4, 16, 20, 30, 36, 38, 40, 48, 177, 187, 189 193, 197, 199, 201, 207, 209, 213, 221, 225, 267, 371, 369, 429, 443, 447, 449, 453, 457, 459, 465	4, 6, 8, 22, 80, 100, 110, 37, 141, 241, 255	3, 9, 24, 52, 58, 60, 92, 98, 100, 102, 110, 113, 115, 133, 137, 139, 143, 147, 157, 231, 297, 303, 305, 307, 333, 357	66, 76, 80, 82, 257, 259, 279, 289, 291, 297, 299, 307, 309, 355, 363, 365, 367, 369, 479	86, 88, 94, 108, 110, 279, 287, 377, 379, 481	74, 76, 78, 80, 88, 90, 94, 115, 135, 137, 141, 169, 171, 175, 199, 201, 203, 223, 257, 265, 285, 307, 313, 381, 411

	Body changes	26, 32, 34, 38, 40, 60, 62, 64, 66, 72, 90, 94, 96, 100, 102, 104, 108, 110, 141, 143, 145, 149, 151, 153, 167, 169, 171, 261, 267, 283, 285, 287, 289, 295	54, 56, 58, 60, 70, 72, 74, 80, 82, 237, 249, 255, 257, 261, 267, 271, 317,	4,18, 149, 153, 155, 313, 315, 393, 399	22, 24, 28, 36, 50, 52, 54, 96, 98, 203	1, 3, 7, 11, 13, 16, 18, 26, 34, 36, 40, 46, 48, 50, 54, 62, 64, 66, 70, 74, 106, 108, 275, 277, 281, 285, 287, 329, 337	50, 189, 195, 211, 213, 231, 237, 239, 281, 283, 285, 317, 329, 339, 341, 345, 347, 355, 357, 389, 391, 393, 395, 399	80, 100, 121, 127, 133, 135, 139, 141, 153, 159, 163, 167, 169, 211, 213, 215, 217, 263, 297, 299, 305, 307, 321, 323, 325, 327, 329, 331, 375	96, 111, 137, 147, 149, 151, 153, 189, 191, 195, 217, 221, 259, 261, 265, 323, 325, 329, 337, 349, 353, 357, 359, 361, 369, 371, 385
Vulnerable Self									
	Control	135, 137, 157, 213, 215, 217, 227	34,38, 40, 58, 104	6, 8, 44, 74, 110, 113, 117, 119, 153, 157, 159, 163, 169	10, 16, 18, 20, 48, 52, 64	159, 249, 341	92, 94, 98, 100	181, 195	84, 110, 111, 115, 131, 133, 135, 137, 185, 197, 199, 287, 293

	Uncertainty	127, 199, 207, 225, 315	50, 115, 143, 147, 159, 169, 171, 173, 175, 369	34, 36, 38, 40, 52, 54, 56, 58, 76, 80, 82, 98, 102, 279, 283, 285, 319, 323, 325, 327, 335, 337, 349, 351, 353, 487, 489, 491, 493, 497	26, 34, 38, 42, 58, 61, 62, 64, 104, 151, 169, 207, 209, 211, 213, 229, 243	22, 82, 84, 86, 88, 92, 94, 96, 155, 157, 159, 161, 164, 167, 169, 171, 173, 175 ,177, 179, 181, 185, 219, 243	84, 92, 123, 125, 135, 177, 179, 181, 241, 245, 247, 251, 253, 293,	80, 203, 207, 255	78, 80, 84, 111, 113, 115, 119, 131, 185, 223, 269, 283, 293, 296, 355, 381, 385

Other's gaze	68, 76, 80, 82, 84, 90, 96, 117, 119, 251, 257, 259, 261	58, 60, 135, 155, 283, 295, 297, 299, 307, 331, 417	20, 22, 24, 42	22, 59, 66, 68, 70, 72, 74, 76, 78, 100, 115, 117, 127, 133, 141, 151, 153, 155, 175, 179	3, 311, 313	199, 203, 205, 281, 283, 285, 287	127, 129, 141, 145, 147, 151, 153, 169, 171, 173, 175, 181, 197, 201, 207, 223, 225, 239, 267, 269, 271, 425, 437	78, 155, 207, 209, 211, 217, 225, 291, 355
Coping Self								
Warrior	20, 22, 52, 78, 177, 179, 185, 187, 193, 197, 209, 241, 243, 253, 307, 309, 333	30, 96, 98, 100, 127, 129, 131, 133, 135, 139, 337, 339, 341, 363, 365, 367	16, 18, 40, 131, 467, 469, 473	24, 30, 32, 34, 36, 56, 84, 86, 137, 151, 157, 159, 179	94, 119, 215, 217, 225, 229, 237, 239, 241, 243, 247, 251, 253, 255, 257, 319, 321, 355	106, 108, 110, 113, 115, 117	80, 84, 88, 90, 104	131, 135, 171, 255, 257, 259, 277, 279, 131, 135, 171, 255, 257, 259, 277, 279, 131, 135, 171, 255, 257, 259, 277, 279

Comparing losses	38, 181, 183, 185, 193, 229, 132, 233, 317	179, 181, 183, 189, 201, 345, 413	12	28	56, 127, 223	399	125, 195, 197, 361, 387, 393, 403	137, 145, 137, 145

	Recovering	20, 22, 24, 179, 189, 195, 277, 285, 299, 301, 305, 309, 315, 319, 321, 323, 325	102, 106, 115, 117, 121,163, 165, 205, 207, 211, 223, 225, 239, 241, 245, 247, 307, 311, 325, 361, 373, 385, 415	52, 56, 143, 145, 167, 231, 325, 239, 339, 345, 347, 355, 363, 365, 369, 371, 373, 427, 429, 437, 439, 441, 483, 485, 505, 509, 511, 513	28, 34, 44, 100, 106, 115 ,119, 125, 149, 153, 187, 189, 193, 195, 197, 223, 225, 229, 231, 235, 239, 237, 253, 257, 263, 265	149, 151, 191, 193, 211, 221, 227, 249 257, 261, 263, 341, 357, 359	60, 64, 104, 131, 137, 139, 143, 147, 151, 161, 163, 167, 169, 173, 175, 183, 185, 191, 193, 209, 221, 223, 225, 227, 229, 233, 257, 261, 265, 267, 271, 273, 305, 315, 317, 319, 321, 327, 331, 337, 349, 371, 373, 375, 388, 401, 403, 405, 411, 415, 441, 445,	94, 96, 121, 125, 179, 181, 229, 231, 259, 261, 263, 293, 295, 301, 333, 335, 345, 381, 385, 389, 405, 407, 417, 419, 467, 485, 501, 503, 505, 509, 513	60, 113, 117, 137, 151, 179, 181, 223, 225, 231, 233, 235, 247, 253, 291, 375, 379, 381, 397, 399, 405, 407, 409

								495, 503, 508		

Section B: Publishable Paper

'A Holistic Approach to Care for Women Struggling after Mastectomy:

An Interpretative Phenomenological Analysis'

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Provide short biographical notes on all contributors here if the journal requires them.

'A Holistic Approach to Care for Women Struggling after Mastectomy:

An Interpretative Phenomenological Analysis'

ABSTRACT

Objective: Due to the limited amount of research found in connection to the subjective embodied experience of women after mastectomy and during rehabilitation, this issue is addressed address in the present research.

Method: Using Interpretative Phenomenological Analysis (IPA), through semi-structured individual interviews, this research sought to explore in depth participants' subjective experiences and perceptions of physical and psychological struggles after mastectomy relating to identity change, self-image and sexual intimacy and how these were embodied in the context of overall wellbeing.

Results: Three major themes emerged from the data: (1) the '*Ill Self*', (2) the '*Vulnerable Self*' and (3) the '*Coping Self*'. The themes illustrate a linear but complex experience of women losing their healthy status and functioning to becoming breast cancer patients, and through to recovery. The findings show the need for a strong professional network of support between counselling psychologists and other relevant healthcare professionals, such support is reliant in the close involvement of clients during assessment and formulation.

Conclusion: The findings of this study add to the body of research on the topic. Participants reported their perceptions and reactions regarding identity change, self-image and sexual intimacy after mastectomy. The participants' wish for a holistic approach to care from specialised services during treatment and recovery was noted. A gap in the provision of psychotherapeutic services in facilitating sensitive communication and following up on the recovery of breast cancer patients was identified within medical teams, at times of extreme physical and psychological struggles.

Key words: Interpretative Phenomenological Analysis, counselling psychology, embodiment, holistic care, illness perception, mastectomy, identity change, self-image and sexual intimacy.

8. Introduction

I introduce the topic by providing some background information on the status of breast cancer occurrence at present and the consequences this has on women's sense of femininity and sexuality. I use past research on the topic to discuss the importance of expanding the knowledge of breast cancer and its implications for female patients. Within that, I present the implications for this research for the field of counselling psychology. That exploration then leads to the purpose of this study, highlighting psychological concerns in negotiating sexuality and femininity during breast cancer rehabilitation. I focus on the women's experiences of illness while within that exploring how women perceive their bodies, femininity, sexuality, relationships and self-concept.

Worldwide, breast cancer is the most common type of cancer found in women, with around 1.7 million cases diagnosed in 2012 (World Cancer Research Fund International, 2018). The latest figures on invasive breast cancer were recorded back in 2015, when 55,122 new cases were found in the UK. Cancer Research UK's latest findings, dating from 2010/2011, show that survival rates are 78% for 10 or more years (females only) and that 27% of cases of breast cancer are preventable (Cancer Research UK, 2018). As the number of diagnosed cases continues to rise, the efficacy of treatment also follows that trend, continuing to increase and allowing survival rates to improve consistently (Matthews, Grunfeld, & Turner, 2017). The consequence of that rise is that women with breast cancer are often found in the difficult position of enduring extensive treatment processes (Siegel, Naishadham, & Jemal, 2013). The issues (physical and psychological) linked to such treatment have been explored by a variety of researchers both from qualitative and quantitative perspectives.

9. Background

9.1. Consequences of breast cancer for femininity and sexuality

Although the treatment for breast cancer varies according to individual cases, by and large it involves one or more of the following: chemotherapy, radiotherapy, hormone treatment and surgery (lumpectomy, mastectomy, breast reconstruction) (White & Hood, 2014). In several cases, treatment and surgery have long-lasting consequences for women's bodies and psyches (Tierney, 2008). A number of studies explored the physical consequences/symptoms

of treatment, with findings pointing at unwanted changes in vaginal lubrication (Knobf, 2002), scarring (Boquiren et al., 2016), painful intercourse, and lower libido and orgasmic dysfunction (Hungr, Sanchez-Varela, & Bober, 2017). Those findings have been reported as seriously troublesome for women's sexual functioning (Safarinejad, Shafiei & Safarinejad, 2013; Boquiren et al., 2016). The psychological consequences of breast cancer treatment have also been found to be significant, with female patients reporting experiences of poorer sense of body image (Donovan et al., 2007), feeling less sexually attractive (Beckjord & Compas, 2007), mood disturbance (Matthews et al., 2017), psychosocial morbidity (Matthews et al., 2017) and lower relationships satisfaction (Ganz, Desmond, Belin, Meyerowitz, & Rowland, 1999). In the case of mastectomised patients, results from a qualitative study showed changes in women's perception of their femininity. Patients reported feeling less attractive and robbed of their feminine identity after mastectomy (Arroyo & Lopez, 2011). The concept of femininity in this case was closely linked to the loss of breast and therefore loss of womanhood (Arroyo & Lopez, 2011).

Parton, Ussher and Perz (2015) argue that treatment consequences are the product of several changes experienced by women with regard to physical appearance and subjective embodied experiences, not only in treatment but also during rehabilitation. Finlay and Langdridge (2012) state that, *"embodiment is the process or state of living in a body"*. According to Glenberg (2010), psychological processes are intertwined with physicality, motor and sensory systems, and emotions. Thus, sustaining that embodiment is a conscious manner of being, the human bodily context – the body being the vehicle/container through which we experience the world inside and outside of us. That is the context through which we relate to others and process our own inner experiences – feelings, thoughts, and behaviours. Its nature is a subjective felt-sense of the body from inside out with regard to intention, attention, posture, movement and other processes. The embodiment of experiences is said to contain several layers, through which the world is perceived, and these are the cultural, personal historical, relational and situational context (Glenberg, 2010).

Breast cancer can be perceived as a persistent loss of functioning, given the length of treatment and/or the long-term symptoms (Raggio, Butryn, Arigo, Mikorski, & Palmer,

2014). The trauma of being diagnosed and treated for breast cancer poses negative effects on psychosexual functioning in women who present with issues related to poor sense of self-worth as a consequence (Henson, 2002). In many cases, psychosexual concerns are experienced in interpersonal relationships due to the long-lasting effects of treatment such as vaginal dryness and lower libido, to cite a few. Such effects can last well after treatment ends, causing relational difficulties with sexual partners and lowering patients' quality of life (Boquiren et al., 2016). *"Sexuality encompasses feelings about one's own body, the need for touch, interest in sexual activities, communication of one's needs to a partner, and the ability to engage in satisfying sexual activities"* (Wilmoth, 1998). According to Henson (2002), however, women's embodiment of sexuality goes beyond intercourse and it surrounds concepts relating to body image, femininity, motherhood and feeling sexually desired. It also involves more sophisticated mechanisms concerning cognition, psychology and sociocultural domains (Henson, 2002).

9.2. Current status of research in the topic

Quality of life in surviving breast cancer patients is of interest to the field of counselling psychology. Findings from previous studies suggest that cancer patients have the need to gain comprehensible information about diagnosis (Kvale & Bondevik, 2008) and explicit knowledge about potential side effects (Grunfeld, Drudge-Coates, Rixon, Eaton, & Cooper, 2013). Issues connected to changes in femininity (Arroyo & Lopez, 2011), sexuality (Beckjord & Compas, 2007), low self-esteem and relationship difficulties (Ashing-Giwa et al., 2004) are among the difficulties identified in breast cancer patients.

The current knowledge available on the topic, though very valuable, seems overly generalised as it largely measures objectively women's overall sex satisfaction with regards to penetrative frequency (Andersen, 2009). An example of standardised questionnaires is the Appearance Schemas Inventory-Revised (ASI-R), used to gain quantitative results with regard to patient's overall appearance satisfaction after cancers that alter physical image (Chua, DeSantis, Teo, & Fingeret, 2014). Although the results of quantitative studies using objective tools provide useful standardised results based on larger data samples, they leave a gap in terms of the experience of individual differences (Slatman, 2014). Quantitative research in the medical

field (oncology and gynaecology) tends to treat patients in a fragmented fashion, by concentrating mostly on the organic aspects of cancer and failing to sufficiently stress the embodiment of the illness.

9.3. Implications for counselling psychology research

A recently published qualitative study by Loaring, Larkin and Shaw (2015) performed an IPA and found that following mastectomy and breast reconstruction, patients expressed concerns of a psychological nature regarding the renegotiation of sexual intimacy in the context of committed relationships during the recovery phase. Sexuality is an evolving lived experience closely interlaced with the way in which individuals perceive their bodies and themselves (Lehmiller, 2014). While considering the implications of this topic for counselling psychology research, I encountered evidence that healthcare professionals often fail to address sexuality in female patients experiencing breast cancer (Hordern, 2000). Lack of knowledge, personal embarrassment, lack of experience, and not feeling responsible for discussing such information were amongst the reasons found for the poor communication between patient and doctor (Stead, Brown, Fallowfield, & Selby 2003). Hordern (2000) also found that the lack of communication may be due to other factors, including a cultural perspective holding the belief that older women with breast cancer are not in the slightest bit focused on sexuality, instead assuming that survivorship is the only important aspect of breast cancer and everything else is secondary (Hordern, 2000). This attitude has been identified as an obstacle for clinicians to foster an open exploration of the meaning of intimacy and sexuality in this population. Hordern (2000) proposes that healthcare professionals should discuss the above-mentioned issues with patients irrespective of age, marital status or other factors. The limitations cited above seem to have given rise to a difficulty in addressing important issues regarding femininity and sexuality with breast cancer patients, therefore neglecting important domains of women's wellbeing.

9.4. Rationale and aims for present research

During my review of the past literature, I found a common overarching theme: women cancer patients felt apprehensive talking about sexual issues with medical staff, and this lack of rapport added to the existing stress relating to the onset of cancer (Anllo, 2000; Fobair &

Spiegel, 2009; Stead et al., 2003). Thus, Attai et al. (2015) found that one of the critical areas in need of improvement regarding breast cancer treatment was communication, alongside education, support and shared decision-making. Also noted in the reviewed studies was the compelling evidence that breast cancer can have a significant impact on woman's wellbeing with regard to self-esteem relating to body changes (Parton et al., 2015), self-image (Marshall & Kiemle, 2005), faith (Fatone, Moadel, Foley, Fleming, & Jandorf, 2007), intimacy (Schover, 1991) and sexuality (Schover, Fife, & Gershenson, 1989), both physically and psychologically.

There seems to be a gap in relation to attending to psychological as well as physiological needs of patients in multidisciplinary teams during breast cancer treatment. Finlay and Langdridge (2012) propose that although embodiment is the link between the human mind and the physical body, in western cultures, the body has traditionally been treated as a biological and material object separated from the mind, holding psychological processes. A limited number of studies exploring the psychological perspective of this topic were found, in comparison with the vast majority stemming from a medical standpoint – oncology or gynaecology (Krychman & Millheiser, 2013), suggesting a split between psychological and medical disciplines. Through research on the unmet needs of breast cancer patients, Soothill et al. (2001) recognised the need to gather and join knowledge from the experiences of various healthcare professionals (nurses, oncologists, psychotherapists, social workers, etc) in providing a comprehensive approach to assessment and treatment. Soothill et al. (2001) argue for the importance of incorporating psychosocial domains in the overall care plan as a way of reducing cancer-related psychological issues in breast cancer patients. Ghane and Sweeny (2013) propose a solution, suggesting that research in health should take the form of incorporating the link between physical and psychological aspects of the self in both disciplines (psychology and medicine).

Due to the current increase in breast cancer in the UK (Cancer Research UK, 2011), concerns about regaining sexual health and managing identity as a way of supporting clients in leading a healthy relational life seem to be an issue worthy of further research. The present research intends to add a qualitative contribution to the existing body of knowledge by providing a

relevant and rich account of women's perceptions of physical and psychological struggles after mastectomy. Developing a broader understanding of women's subjective, embodied experiences of identity change after illness, self-image and sexual intimacy after mastectomy is an area of great concern in helping survivors make sense of such experiences and improving their quality of life (Reich, Lesur, & Perdrizet-Chevallier, 2008).

10. Method

10.1. *Procedures*

Interpretative Phenomenological Analysis (IPA) is a qualitative approach to research founded by Jonathan Smith in the mid-1990s. It derives from the philosophic inquiry of Husserl who recommended phenomenologists to *"go back to the things themselves"* – meaning that research should concentrate on the participants' experiences, yet through the lens of the researcher's interpretation of the given experience (Smith, Flowers, & Larkin, 2009). IPA is widely used and recommended in the fields of health and counselling psychology and it is often applied to investigate the nature of illness and its perceptions (physically/psychologically) (Smith, 1996).

The present study explores in depth my participants' experiences of femininity and sexuality in the context of breast cancer through an interpretative investigation. IPA allowed me to obtain valuable insights into the nature and quality of my participants' embodied relational experiences (Willig, 2013). Unlike in quantitative approaches, where researchers work towards either proving or refuting a hypothesis, I analysed the data by bringing my own interpretations about my participants' lived experiences based on my chosen humanistic framework, in combination with my strategic and embodied/personal reflections on the topic (Smith et al., 2009).

10.2. *Participants*

I approached this study using purposive sampling by choosing selective participants through a common 'lived experience' based on shared characteristics of a population to fit the study's objectives or the phenomena being studied (Smith et al., 2009). The utilisation of a purposive sampling strategy provided scope for the recruited participants to fall within a specific central

part criterion, ensuring, therefore, that I gained a homogenous sample (Smith et al., 2009). A sample of eight participants was chosen with the view to prioritising the quality of the data gathered rather than the quantity (Smith et al., 2009). It was imperative that my participants fitted my criteria (female, above the age of 18 years and having undergone a mastectomy). I focused on this population due to breasts often being regarded as an important part of women's sexual identity.

Table I. Participant's information

Participant	*Means of recruitment*	*Demographics*	*Mastectomy Outcome*
FEM01 (Abbi)	Charity shop ad	40, White British, married	Reconstructed from own tissue
FEM02 (Barbara)	University ad	75, White British, married	No reconstruction
FEM03 (Carol)	University ad	45, White British, married	Unsuitable for reconstruction due to previous health issues
FEM04 (Deanne)	Nail bar ad	60, White European, widowed and then open relationship	No reconstruction
FEM05 (Elena)	Word of mouth	50, White British, married	No reconstruction
FEM06 (Fiona)	University ad	60, White British, married	Silicon implant
FEM07 (Gabi)	University ad	55, White British, married	Silicon implant

| FEM08 (Heather) | University ad | 50, White British, married | Silicon implant |

10.3. Data collection

My priority in relation to ethical considerations was the wellbeing of my participants. Prior to beginning the research, ethical approval was sought and acquired by City University of London Ethical Committee and in accordance with the BPS Division of Counselling Psychology 'Professional Practice Guidelines', The BPS 'Code of Ethics' (2009) and the HCPC 'Standards of Proficiency – Practitioner Psychologists' (2018). In order to protect participants' identities and their confidentiality, I replaced individual names with fictitious ones, as well as altered their ages and any personal identifiable demographic details. A series of safeguarding procedures (phone triage and information sheet) were followed to ensure this project was ethically appropriate.

I personally collected the data via face-to-face, individual, open-ended and semi-structured interviews. Interviews were carried out at the university building with the exception of two participants who chose to be interviewed at their homes. Interviews lasted approximately 60 minutes. I conducted a pilot interview with one participant and that interview was not included in the study. The aim of the pilot interview was to test the quality of my interview questions with regard to language appropriateness, eloquence, but also to gain the participants' feedback regarding the quality of the questions. I explored my participants' in-depth accounts of the phenomena through a series of about 15 flexible questions, including a few prompts to invite participants to elaborate further on their answers. The non-directive interview schedule began with questions about the individual's experiences of cancer in broad terms, gradually narrowing this down to more in-depth accounts, and finalising the interview with the exploration of their current wellbeing as the first step into the debriefing process in an organic fashion (Smith et al., 2009). Debriefing took as long as the participants needed and the relevant contacts for specialised psychological services were offered.

10.4.   *Transcription & transcripts*

According to Smith and colleagues (2009), the transcription process should include all words spoken by the participant and the researcher, including overlaps in speech, repetitions and pauses. Since I viewed the transcription phase as of paramount importance for the process of data interpretation and description, I followed Smith and colleagues (2009) suggestions and transcribed the data without any grammatical corrections.

10.5.   *Methodological considerations*

Although concepts of validity and reliability are often associated with quantitative data analysis, assessing the quality of qualitative studies is also essential to ensure robustness of findings (Smith et al., 2009). I followed Yardley's (2000) suggested set of four criteria, which helped to ensure validity in this qualitative research.

My commitment and rigour is illustrated through my work's transparency and coherence throughout the research process, and includes my commitment to keep a reflective diary regarding the context of the obtained sample (Willig, 2013), a clear report of the research process and its methodology, and appropriate comments on the data acquired in terms of verbatim quotes of my participants (Smith et al., 2009).

10.6.   *Analytic strategy*

Smith and colleagues (2009) suggested a set of IPA analytical methods in the form of four steps and stressed the flexibility with which such guidelines were to be applied (p. 79). The four steps suggested by Smith and colleagues (2009) are step one - reading and re-reading, step two - initial noting, step three – developing emerging themes and step four –searching for connections across emergent themes. In the step one, the researcher is expected to be immersed in the original data while listening to the audio recording of each interview. In the step two, the researcher begins the detailed analysis of the data, exploring content descriptively, linguistically and conceptually in order to capture the essential quality of what has been expressed in the text and while staying close to the meaning attributed by participants. In the third step, the researcher begins searching for emergent themes by looking into keeping the complexity of data while aggregating the details in to a reorganisation of the

data. In step four, the researcher looks maps out a coherent and connected net of how the themes fit in together as a whole (Smith et al., 2009).

Although it is not common practice to include previous literature within the presentation of an IPA analysis, I will present an account of how this literature was brought into my analysis process. The transcripts were analysed completely separately and without reference to previous literature, therefore my insights were not shaped by it during the analysis process. I wove the references to the past literature into the analysis section during the write up process, in order to provide the reader with a sense of how the outcomes of my analysis related to previous research. My data analysis process was based on my own interpretation of my participant's lived experiences and in line with my chosen therapeutic approach –humanistic, combined with reflective practices (strategic and embodied) on the subject (Smith et al., 2009).

11. Results

Table II. Framework of master and sub-themes

THEMES	SUB-THEMES
I. Ill Self	*Shock*
	Pain
	Body changes
II. Vulnerable Self	*Control*
	Uncertainty
	Other's gaze
III. Coping Self	*Warrior*
	Comparing losses
	Recovering

11.1. **Major** *Theme I: 'Ill Self'*

The Ill Self major theme emerged from participants' shared feelings, beliefs and responses to a range of embodied physical and psychological experiences as they were notified of a surprisingly and serious change for the worse in their health. All participants expressed the

difficulties faced in this first emergent stage of diagnosis and how that seemed to shift their position from being healthy to becoming a patient.

11.1.1. Sub-theme I: 'Shock'

All participants unanimously described their initial response to breast cancer diagnosis with the word 'shock', even though a few were sure that the test results were not going to bring good news.

In the extract below, Heather described a visible physical reaction to receiving her diagnosis when her body seemed to shut down at the knowledge of her diagnosis. It is as if she could not take such shock and so her body switched off on the spot – a typical 'freeze' reaction to shock (Fink, 2016).

> *"My initial response was I went into shock and then passed out in the consulting room. […]" (Heather, 54)*

Throughout all participants' accounts, the distress of their experience of receiving a breast cancer diagnosis was evident. The shared sub-theme of shock was a clear reaction when analysing the accounts individually and collectively. Following that initial shock, participants began to describe the pains (emotional and physical) that were experienced.

11.1.2. Sub-theme II: 'Pain'

The 'pain' sub-theme encompasses a wide variety of bodily (physical) and mental (psychological) pain relating to illness.

Gabi talks about having an intrinsic knowledge based on her experiences of stress in correlation to physical pain. Interestingly, she feels there's a significant connection between psychological struggles and physical pain but she seems to doubt her self-knowledge about her states. She ends the quote suggesting that the psychological changes brought by breast cancer were trickier to manage in comparison to the physical changes.

"I had some pains in my breast, I was very stressed at the time and I don't know whether this is psychological or not, but I felt that when I was stressed the pains became more increased, and I don't know whether I made that up, but I really did feel it. [...] Very, it was very, emotionally and physically, but the physical thing we can cope with…" (Gabi, 86/94)

This sub-theme underlines how the physical pain of illness gets closely intertwined with the psychological struggles in relationships with oneself and with others as roles get reversed. Although a lot of pain has already been experienced at that stage, further and more explicit changes are ahead of participants.

11.1.3. Sub-theme III: 'Body changes'

'Body changes' is an important sub-theme throughout the data and deals with the final and most explicit stage of becoming the 'Ill Self', as deep physical changes occur quickly following diagnosis.

Elena talks about her experiences of how the changes in her physiology were closely related to psychological processes such as the change in perceptions while interacting with her body. She describes feeling detached from the healthy breast after losing the ill breast. She seems to be describing a double loss, even though the healthy breast remained physically intact. Elena's reaction to the stress of physically losing her ill breast and losing touch with her healthy breast could be interpreted as an attack on her sexual wellbeing which is causing her distress. Physical changes after breast cancer were found to produce a range of unwanted feelings (e.g. fear), which have a negative effect on mood. Unwanted feelings are found when the stressor impairs functioning (Dougall & Baum, 2001). The negative meaning attributed to the stressor (breast cancer) by Elena may have given rise to feelings attached to loss of control over her health and subsequently have increased distress in the form of rejection of her healthy breast (Breslau, 2003). Breast symmetry is strongly associated with feminine ideals of beauty (Eichenbaum & Orbach, 2012) and it seems as though for Elena it was challenging to accept that her breasts were not symmetrical after having had a mastectomy and no reconstruction. This imbalance in her breast appearance may have translated into her experience of detachment from the remaining breast, however healthy it may have been.

"So I've not only lost the one on the right, but the one on the left was never, I didn't feel, it's funny to say you don't feel quite as attached to it afterwards, but I didn't) [...] I think I just I feel a little bit separate from it now." (Elena, 5/11)

'Body changes' summarises the experiences of participants who shared difficult feelings of grief about the physical changes after breast loss – whether reconstruction was an available option or not. This new role – Ill Self – was established through the embodied experience of illness and it is the first stage of becoming a breast cancer patient. It is followed by a phase of deep physical and emotional vulnerability.

11.2.   *Major Themes II: 'Vulnerable Self'*

This theme concerns the experience of participants' exposed vulnerability based on 'control' issues in relationship dynamics, 'uncertainties' relating to their future and feelings of exposure to the 'other's gaze'.

11.2.1.   *Sub-theme I: 'Control'*

Broadly, this sub-theme refers to choices or the lack thereof in relation to self and others but also in relation to important events surrounding the experience of breast cancer.

In the extract below, Carol talks about taking control in two different situations related to her body changes. First she expresses the need to control her hair loss by willingly shaving her head to prevent gradual hair loss as consequence of chemotherapy. Then she talks about the powerful act of choosing to have a mastectomy rather than living with the uncertainty of keeping an untrustworthy breast living in her body. Carol's accounts suggest that she felt strongly that her breast was a potential hazard to the integrity of her body and she wanted to remove it. As adults, when we fall sick, we are expected to regain control over our bodies and when we fail to do so, even for a short period, all efforts are concentrated on regaining this control as quickly as possible (Frank, 2013). Past studies have found that illnesses limit patients' control over their bodies and over their life's circumstances. Patients described their lives as more valuable through the levels of quality of life gained when in control of their physiology. The empowerment of self is linked to the ability to make important life choices (Rodríguez-Prat, Monforte-Royo, Porta-Sales, Escribano & Balaguer, 2016).

"It was nice because I could take control! So yeah, so the hair wasn't falling out, it was [pause] me choosing to have my head shaved, so that was, I knew that I needed to control that, rather than it just happened to me. [...] I can't, I just want the surgery. I just want everything out of me, so just cut it out!" (Carol, 157/100)

'Control' speaks volumes about the power struggles of surrendering emotionally and physically to the care of others when feeling unable to tend to oneself. It also refers to taking control of certain situations and interactions as often as possible as a way of regaining/retaining some power over what has been happening since the breast cancer diagnosis. The literature of general illnesses frequently highlights the importance of fostering and sustaining a trustworthy bond between patient and healthcare professionals for the reinforcement of treatment adherence (Aldaz, Treharne, Knight, Conner & Perez, 2018). While analysing my participants' reports about managing vulnerable feelings I noticed that taking control and surrendering control were helpful strategies in maintaining a sense of empowerment over some critical aspects of their ill condition. Taking control, for instance, was perceived as actively directing which way participants wished to take their future, namely making choices that were suitable and in line with their sense of self. Surrendering control to the care of others, however, was interpreted as liberating for other participants who chose to take a less conflictual approach in navigating through the already turbulent waters of the illness. Both strategies come with drawbacks and advantages. While those who chose to take control felt more empowered in their position as patients, this also implied an internal emotional conflict of struggling to accept a vulnerable position. By contrast, surrendering control in my participants' case seemed to take place through a trustful acceptance that a care plan had been designed and implemented to take care of their important needs by qualified professionals who were skilled in the position of carer. However, Rodríguez et al. (2016) found that some patients who described an inability to take care of themselves ended up feeling a loss of self-identity.

11.2.2.   Sub-theme II: 'Uncertainty'

'Uncertainty' refers to a range of doubts about self, others and the world. Through this research I have found that illness is strongly associated with the loss of predictability. The

loss of predictability seems to have caused participants to feel vulnerable across a variety of life domains and about a variety of important topics strongly tied up with everyday life events previously taken for granted.

Frank (2013) talks about the shared experience of a person's ill body 'for' each other, calling it 'other-relatedness'. This concept concerns how the shared condition of inhabiting bodies serves as the foundation for empathic relationships between people. It seems to apply to Abbi's situation, when she describes being faced with her mortality. Abbi shares the realisation that her life could end as result of breast cancer and perhaps life's order would be altered, potentially causing pain to her mother. Sitting with the uncertainty about whether her life is going to end prematurely (before her mother's) seems to have triggered in Abbi a worry about her close family relationships and how much pain her physical departure could cause to the family's structure. Although brief, this account expresses an important thread of the body in pain and the body that causes pain to others as both an individual and collective process. *"She sees others who are pained by her pain"* (Frank, 2013, p. 36).

> *"Yeah, erm, I think [pause] I think it made me realise that, [pause] you know, you could die. […] If my mum has to bury me!" (Abbi, 207/315)*

'Uncertainty' summarises broad feelings of vulnerability in the face of changes brought on by the illness. Amongst the vulnerable feelings of the participants were the contemplation of their own mortality, the vulnerability of their bodies to reoccurrence, a loss of trust in their bodies, anxieties around seeking a new romantic partner during recovery, and missing regular professional care. The vulnerable feeling of uncertainty led to self-doubt and fears about how participants might be perceived by others.

11.2.3.   Sub-Theme III: 'Other's Gaze'
This sub-theme refers to my participants' experiences of self-concept as they question their concepts of femininity and sexuality relating to body exposure to other's judgement.

Deanne shared a lack of satisfaction with her body image in interpersonal relationships. She was faced with being a single woman with a single breast and wondering whether she would be perceived as sexy after mastectomy, which showed her concern about men's gaze. In her comparison with women who have two breasts I noticed her disappointment about the loss of her breast and I sensed a feeling of inadequacy in comparison with someone who had not had any bodily modifications. Arroyo and Lopez (2011) argued that the loss of a breast leads patients to experience a poor sense of self-worth and a changed sense of femininity. That decline in self-worth was found to be directly linked to the loss of a body part that is highly valued by women and men as an important erotic object in interpersonal intimacy. Having the breast removed as a result of mastectomy can impact directly on women's perceptions of being sexually desirable to their partners.

> *"And with my partner who left me for this younger woman is [pause] I realise that I often think of, I'm not jealous with her, and when he was like that it's not man I really want, and so on, but I often think that she has two breasts…" (Deanne, 78)*

As a major theme, the 'Vulnerable Self' encompasses feelings of embodied exposure (physically and emotionally) to the scrutiny of others. That exposure had the potential for rejection/acceptance from others as participants were faced with deep and unwanted changes in their feminine appearance and sense of self. Participants' journeys through this second phase where they had their raw vulnerabilities exposed triggered their need to find a suitable way of expressing and coping with the difficulty of the feelings they were left with.

11.3.   *Major Themes III: 'Coping Self'*

The 'coping self' expresses the resources my participants used to recover from illness and regain wellbeing while going through losses.

11.3.1.   *Sub-theme I: 'Warrior'*

The 'warrior' sub-theme talks about my participants' survival mode – the experience of psychological robustness in the face of a potentially life-threatening disease.

Elena shares her sense of feeling under pressure to cater for everyone else – as a mother and a wife – and how she viewed her position as a breast cancer patient as being no different from the time when she was healthy. She seems to be experiencing the weight of her obligations in sparing her family from suffering, even though her emotional resources are low. Eichenbaum and Orbach (2012) argue that women's social role in society is based on nurturing others above their own needs. That can be detrimental to women's wellbeing as the emotional catering for others' feelings is often unbalanced and not reciprocal. In the extract below, I interpret Elena as sharing her social learning about the emotional deprivation that is expected from women when faced with challenging situations.

> *"Yeah, but you also feel under a huge obligation to make everything alright for everybody.*
> *[...] Absolutely! Yeah it had to be business as usual [giggles] as far as I saw." (Elena, 237)*

The 'warrior' expresses participants' reactions to a range of vulnerable emotions, including anger and sadness. It shows how participants resisted accepting a vulnerable position in relation to illness by creating a 'strong' façade and/or seeking a less emotional and consequently more intellectual space. That coping strategy seems to have been developed as a way to spare their loved ones from pain while they managed their difficulties rationally rather than "falling apart" or being perceived as weak.

11.3.2.   Sub-theme II: 'Comparing losses'

This sub-theme illustrates how participants made sense of moving forward while taking stock of what had happened during illness.

Barbara states that she shared her feelings and perceptions of her breast cancer with very few people during the process from illness to wellness. She seems to be making sense of why it might be helpful to talk by acknowledging the value of professional help – even though my role is that of a researcher on this occasion. Barbara's accounts of the importance of sharing her story in a contained and safe environment are in line with past research findings that have identified the offer of psychological support in this journey from illness to recovery as valuable (Fobair et al., 2006).

"Maybe because I don't talk to people all the time it feels almost therapeutic to talk about it. I don't have to go away from here feeling that I have told you too much…" (Barbara, 413)

'Comparing losses' was an important part of coping, as it seems to have been the place where repair began. Participants compared what was lost during the crisis and what could be repaired moving forward, while sharing their reflections about the extent to which their roles had shifted since the breast cancer diagnosis. They also compared their experiences of sharing with others and offered their thoughts on the importance of specialised care during the recovery phase.

11.3.3. Sub-theme III: 'Recovering'

'Recovering' is about the systems (support) that my participants had available to help them get through illness to regain wellbeing and improve their quality of life after mastectomy.

Fiona conveys a search for a suitable space where she can express her emotions as a way of validating her experience while unburdening her concerns. Past research shows that patients recovering from breast cancer have shared their issues in addressing sexual concerns and built a narrative of experienced events as a way of improving quality of life (Reese, Porter, Bober, & Lapore, 2017).

"So it was just, and as much as anything, it's expressing it really, erm and realising what you're feeling, that is an important thing about that, there was probably nothing they could do, but it's just nice to have got it off your chest, in a way." (Fiona, 305)

The 'Coping Self' highlights my participants' concerns about having an open and safe environment in which to express their emotions regarding their altered sense of femininity and sexuality. The 'Coping Self' seems to be about refocusing, regaining balance, improving the quality of relationships and recalibrating life's priorities as participants move into wellness again. These women seem to have come through a long and dark tunnel in their journey from wellness to illness and then back again to share their narrative of recovery.

Creating a network of support that relies on the close involvement of clients during assessment and formulation seems like an important point when designing a holistic treatment plan based on individual client needs (identity, relationships, sexual recovery, body image, etc.), while accounting for physical and psychological needs of service users is paramount for the recovery of quality of life after breast cancer.

12. Discussion

12.1. Introduction

I discuss the findings of my Interpretative Phenomenological Analysis in relation to my research question – *how breast cancer patients experience (physically & emotionally) their femininity and sexuality during the rehabilitation phase of mastectomy*. Initially, I situate my findings within a broader frame of research. The master themes found were the 'Ill Self', 'Vulnerable Self' and 'Coping Self'. Then, I suggest some future directions, focus, and identified gaps for further research, while also exploring the strengths and limitations of the present study. Following that, I end this article with a brief summary and conclusion of my study.

12.2. Summary of findings

The 'Ill Self'

Participants shared their embodied experiences of femininity and sexuality through the exploration of how meaning was obtained out of that unexpected emerging identity, by addressing new functions to their bodies: once carers, now being cared for. They went from leading fully functioning and fulfilling lives to becoming cancer patients who partially and temporarily lost their healthy identity and autonomy. Such experiences led to the development of a new role – 'Ill Self' – as participants learned about breast cancer diagnosis and its physical and psychological implications. This initial stage preceded a state of embodied exposure of vulnerabilities.

The 'Vulnerable Self'

This stage expresses power struggles in relation to the events unfolding after illness, reflecting participants' 'uncertainties' about what the future holds, as they move into the unsettling role of a patient. The fear of 'other's gaze' or – in other words – of being rejected, and the desire to be accepted despite significant changes in their physical feminine appearance, are also expressed in this position.

The 'Coping Self'

This final step was discussed through a 'warrior' figure, which was identified as a survival mode activated to manage unwanted vulnerable feelings. The warrior seems to have emerged based on the need of participants to cope with a changed and fragile sense of self. The difference between actual warriors and my participants is that these women were not prepared for combat but rather were taken by surprise. Despite that, they fought with the weapons they had available. This final major theme also talks about women's inclinations to 'compare losses' by taking stock of what was lost/gained in the process of illness and discusses their need to continue to thrive and move towards 'recovery' and full functioning despite all the mishaps along the way.

12.3.   *Summary of discussion in relation to past research*

This study discusses its findings by building on the qualitative and quantitative research on femininity and sexuality after mastectomy and relating this to women's wellbeing. The 'Ill Self' major theme conveys participants' feelings, beliefs and responses to a range of physical and psychological experiences in the context of illness. All participants expressed the difficulties faced in this first stage of diagnosis and how that seemed to have shifted their position from being healthy to becoming a patient. Evidence suggests that a change in identity through the experience of breast cancer diagnosis, followed by an altered self-image, can trigger a variety of psychological processes and consequently a decline in wellbeing status (Hungr et al., 2017). That decline in wellbeing may be understood as the symbolic loss of health through illness, a type of grief that has been fairly recently recognised by grief theorists (Pillai-Friedman & Ashline, 2014; Boss, 2009). The psychological responses to breast cancer have been described as a constant chain of feelings that vary according to the stages of illness

(Breslau, 2003). The exploration of my participants' connections between physical and psychological pain (Fink, 2016) is an important part of this major theme, as disambiguating one from another proved a challenge, supporting embodiment theories that mind and body are interwoven (Carel, 2012).

The 'Vulnerable Self' is the second major theme and it was identified through participants' exposed vulnerability in relational dynamics but also vulnerability to the challenges presented by illness. Within this second theme, I discovered that participants' power conflicts with others (doctors, partners), exemplifying their struggles in surrendering and taking power. Due to fear and anxiety, some participants kept a tight grip on having as many choices as possible as a way of maintaining some autonomy and control over their lives (Rodríguez-Prat, Monforte-Royo, Porta-Sales, Escribano, and Balaguer, 2016), whereas others gladly surrendered control to doctors' care (Aldaz, Treharne, Knight, Conner, & Perez, 2018). The 'Vulnerable Self' theme also illustrates women's concerns about the uncertainties that lie ahead and the feelings of exposure to the other's gaze during the recovery process. Participants' uncertainties gave rise to doubts about self-concept with regard to how others would perceive them (Marshall, Lengyel, & Menec, 2014) and about their own mortality and the pain that could cause their loved ones (Frank, 2013). 'Other's gaze' is the last stage of participants' changes in perception about self, others and the world. It encompasses my participants' concerns, attitudes and perceptions of themselves and on how others might view them after the body changes – mostly regarding mastectomy (Arroyo & Lopez, 2011).

The 'Coping Self' is the third and final identity and it is where participants' needs to gather their remaining emotional resources emerged through the figure of the warrior. It illustrates participants' needs to keep a brave face as a way of overcoming vulnerable feelings. Participants stated that they *"can't afford to fall apart"*, otherwise the family system might collapse, and this was interpreted as the embodiment of painful feelings, which could lead to a failure in looking after their families (Eichenbaum & Orbach, 2012). In comparing losses, participants shared feelings and perceptions of the process of illness and how it might be helpful to access professional psychological help, supporting past research findings that have identified the offer of psychological support in this journey from illness to recovery as

valuable (Fobair et al., 2006). Lastly, 'recovering' points out the need for support systems to help participants overcome breast cancer and re-establish wellbeing. Providing support for patients can improve the recovery of breast cancer by offering a space for sharing sexual concerns and building a narrative of illness (Reese, Porter, Bober, & Lapore, 2017).

12.4. Limitations

One of the limitations of the present study lay in my decision to select a purposive sample, as per Smith et al.'s (2009) suggestions. Despite that being regarded as the best option in an IPA due to its aim of investigating the experiences of a small (in this case, eight participants) and fairly homogenous group, it limited the generalisation of my findings (Smith et al., 2009). My participants were all women above the age of 18 who had undergone a mastectomy after a diagnosis of breast cancer. The recruitment process occurred mainly through placing adverts within my university grounds, which in turn left me with a sample of participants from a similar socio-economic, ethnic and educational background. My participants were all heterosexual and currently sexually active – either in a committed or a non-committed relationship setting with one or more partners.

If I'd had more time and resources, I could have explored a sample of women of varied sexual orientation, and from a varied socio-economic, cultural, ethnic and educational background. I believe that would have provided a broader knowledge about commonality and dissimilarities across experiences of femininity and sexuality after mastectomy.

12.5. Strengths

While considering the strengths of this study, I reflected on the chosen methodological approach (IPA) and its in-depth focus on the meaning of individual lived experiences. As such, I believe the qualitative nature of this research is strength in itself. It adds an in-depth analysis of women's experience of their sense of femininity and sexuality after mastectomy by building on the existing quantitative data on the topic. The phenomenological approach of IPA caters for the topic's sensitivity by enquiring into participants' experiences of a phenomenon and for these reasons has been found to be increasingly useful in research studies relating to illness and quality of life (Van Manen, 1990; Moustakas, 1994). The gaps

left in previous generalised quantitative results were addressed in the present study by giving voice to women's shared embodied experiences of femininity and sexuality. Thus, the present study tells a story across time, where women recovering from breast cancer were able to explore their emotional and physiological reactions as well as their coping skills and the difficulties triggered at the moment of diagnosis and throughout rehabilitation.

12.6.   *Future directions & clinical implications*

Considering the study's findings discussed above and in the light of past research on the topic, some future directions are suggested. The qualitative in-depth results in the present study highlight women's concerns with regard to the need for a network of support. Such support needs to be holistic in its approach in order to help with the management of changes in self-concept after illness. Although the present participants reported having a preference for one type of support over another, all women unanimously needed some type of support for their recovery process to be successful. Amongst the networks of support found were close family, friends and partners, as well as a broader environmental support from professionals such as psychotherapists, oncologists, nurses, online platforms and educational material provided by healthcare professionals or found online through independent research. It seems pertinent to continue exploring what are the best-suited options regarding the network of support in a variety of cases, according to what is available for different groups. My results are in line with the government's agenda for care, which proposes a holistic approach to assessment and treatment of breast cancer as a way of ensuring quality of life.

Lastly, future quantitative research could also explore whether the present findings hold for a larger group, and in-depth research could explore specific issues in certain demographics (e.g. differences and similarities in experiences for women in same-sex relationships; or women from different ethnicities and across different ages).

13. Conclusion

Key findings of the present study reveal participants' embodied struggles with changes in identity (healthy-ill) after breast cancer, at diagnosis and throughout recovery. Participants reported their perceptions and reactions regarding identity change, self-image and sexual

intimacy after mastectomy. My results are congruent with findings from the reviewed literature on cancer patients' experiences of illness (e.g. Aldaz et al., 2018). Participants' wish for a holistic approach to care from specialised services during treatment and recovery was noted. A gap in the provision of psychotherapeutic services in facilitating sensitive communication and following up the recovery of breast cancer patients was also identified within medical teams.

14. Acknowledgements

15. Conflict of interest

16. References

Aldaz, B. E., Treharne, B. E., Knight, R. G., Conner, T. S, & Perez, D. (2018). "It gets into your head as well as your body"/ The experiences of patients with cancer during oncology treatment with curative intent. *Journal of Health Psychology*, *23*(1), 3-16.

Andersen, B. (2009). In sickness and in health: Maintaining intimacy after breast cancer recurrence. *The Cancer Journal*, *15*(1), 70-73.

Anllo, L. M. (2000). Sexual life after breast cancer. *Journal of Sex & Marital Therapy*, *26*, 241-248.

Arroyo, J. M. G., & López, M. L. D. (2011). Psychological problems derived from mastectomy: A qualitative study. *International Journal of Surgical Oncology*, 1-8. Retrieved from https://doi.org//10.1155/2011/132461

Ashing-Giwa, K. T., Padilla, G., Tejero, J. Kraemer, J., Wright, K., Coscarelli, A., ... Hills, D. (2004). Understanding the breast cancer experience of women: A qualitative study of African, Asian American, Latina and Caucasian cancer survivors. *Psycho-Oncology*, *13*, 408–428.

Attai, D. J., Cowher, M. S., Al-Hamadani, M., Schoger, J. M., Staley, A. C., & Landercasper, J. (2015). Twitter social media is an effective tool for breast cancer patient education and support: Patient-reported outcomes by survey. *Journal of Medical Internet Research*, *17*(7), e188.

Beckjord, E., & Compas, B. E. (2007). Sexual quality of life in women with newly diagnosed breast cancer. *Journal of Psychosocial Oncology*, *25*(2), 19-36.

Boquiren, V. M., Esplen, M. J., Wong, J., Toner, B., Warner, E., & Malik, N. (2016). Sexual functioning in breast cancer survivors experiencing body image disturbance. *Psycho-oncology*, *25*(1), 66-76.

Boss, P. (2009). The trauma and complicated grief of ambiguous loss. *Pastoral Psychology*, *59*(2), 137-145.

British Psychological Society (BPS) (2009). Code of Ethics and Conduct. Retrieved on the 10th June 2018 from: http://www.bps.org.uk/search/apachesolr_search/code%20of%20ethics%20and%20conduct

Breslau, E. S. (2003). The continuum: Somatic distress to medicalization in women with breast cancer: Theoretical and empirical assessment. *Gender Perspectives on Health and Medicine*, 131-180. Published online 9 Mar 2015. Retrieved from https://doi.org/10.1016/S1529-2126(03)07005-X.

Cancer Research UK (2018). Breast cancer: Choosing between lumpectomy and mastectomy. Retrieved on the 18th November 2018 from: https://www.cancerresearchuk.org/about-cancer/breast-cancer/treatment/surgery/lumpectomy-or-mastectomy

Cancer Research UK (2018). Cancer statistics for the UK. Retrieved on the 18th July 2018 from: https://www.cancerresearchuk.org/health-professional/cancer-statistics-for-the-uk.

Cancer Research UK (2011). Data on breast cancer statistics. Retrieved on the 10th June 2018 from: http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/breast-cancer#heading-Zero.

Carel, H. (2012). Phenomenology as a resource for patients. *Journal of Medicine and Philosophy*, *37*(2), 96-113.

Chua, A. S., De Santis, S. M., Teo, I., & Fingeret, M. C. (2015). Body image investment in breast cancer patients undergoing reconstruction: Taking a closer look at the Appearance Schemas Inventory-Revised. *Body Image, 13*, 33–37.

Donovan, K. A., Taliaferro, L. A., Alvarez, E. M., Jacobsen, P. B., Roetzheim, R. G., & Wenham, R. M. (2007). Sexual health in women treated for cervical cancer: Characteristics and correlates. *Gynecologic Oncology, 104*, 428–434.

Dougall, A. L., & Baum, A. (2001). In A. Baum, T. A. Revenson, & J. E. Singer (Eds.), *Handbook of health psychology* (pp. 709–725). Mahwah, NJ: Lawrence Erlbaum

Associates.

Eichenbaum, L., & Orbach, S. (2012). *Understanding women: A feminist psychoanalytic approach.* New York: Basic Books.

Fatone, A. M., Moadel, A. B., Foley, F. W., Fleming, M. & Jandorf, L. (2007). Urban voices: The quality-of-life experience among women of colour with breast cancer. *Palliative and Supportive Care*, *5*, 115–125.

Fink, G., & Elsevier Freedom Collection EBA (2016). *Stress: Concepts, cognition, emotion, and behaviour.* London: Academic Press, an imprint of Elsevier.

Finlay, L., & Langdridge, D. (2012). Embodiment. In W. Hollway, H. Lucey, A. Phoenix, & G. Lewis (Eds.), *Critical readings in social psychology*. Milton Keynes: The Open University.

Fobair, P., & Spiegel, D. (2009). Concerns about sexuality after breast cancer. *The Cancer Journal (Sudbury, Mass.)*, *15*(1), 19-26.

Fobair, P., Stewart, S. L., Chang, S., D'Onofrio, C., Banks, P. J., & Bloom, J. R. (2006). Body image and sexual problems in young women with breast cancer. *Psycho-Oncology, 15*, 579–594.

Frank, A. W. (2013). *The wounded storyteller: Body, illness, and ethics.* (2nd edition). Chicago and London: The University of Chicago Press.

Ganz, P., Desmond, K., Belin, T., Meyerowitz, B., & Rowland, J. (1999). Predictors of sexual health in women after a breast cancer diagnosis. *Journal of Clinical Oncology, 17*(8), 2371–2380.

Ghane, A., & Sweeny, K. (2013). Embodied health: A guiding perspective for research in health psychology. *Health Psychology Review*, *7*(sup1), S159-S184.

Glenberg, A. M. (2010). Embodiment as a unifying perspective for psychology. *Wiley Interdisciplinary Reviews: Cognitive Sciences*, *1*(4), 586-596.

Grunfeld, E. A., Drudge-Coates, L., Rixon, L., Eaton, E., & Cooper, A. F. (2013). "The

only way I know how to live is to work": A qualitative study of work following treatment for prostate cancer. *Health Psychology: Official Journal of the Division of Health Psychology*, American Psychological Association, *32*(1), 75.

Henson, H. K. (2002). Breast cancer and sexuality. *Sexuality and Disability, 20*(4), 261-275.

Health and Care Professions Council (HCPC) (2018). Standards of proficiency for ractitioner psychologists. Retrieved on the 8th June 2018 from: http://www.hcpc-uk.org/assets/documents/10002963SOP_Practitioner_psychologists.pdf

Hordern, A. (2000). Intimacy and sexuality for the woman with breast cancer. *Cancer Nursing*, *23*(3), 230-236.

Hungr, C., Sanchez-Varela, V., & Bober, S. L. (2017). Self-image and sexuality issues among young women with breast cancer: Practical recommendations. *Revista De Investigacion Clinica; Organo Del Hospital De Enfermedades De La Nutricion, 69*(2), 114.

Knobf, M. T. (2002). Carrying on: The experience of premature menopause in women with early stage breast cancer. *Nursing Research*, *51*, 9-17.

Krychman, M., & Millheiser, L. S. (2013). Sexual health issues in women with cancer. *Journal of Sexual Medicine*, *10*(1), 5-15.

Kvale, K., & Bondevik, M. (2008). What is important for patient centred care? A qualitative study about the perceptions of patients with cancer. *Scandinavian Journal of Caring Sciences*, *22*(4), 582-589.

Lehmiller, J. J. (2014). *The psychology of human sexuality*. Chichester, West Sussex, UK: Wiley Blackwell.

Loaring, J. M., Larkin, M., Shaw, R., & Flowers, P. (2015). Renegotiating sexual intimacy in the context of altered embodiment: The experiences of women with breast cancer and their male partners following mastectomy and reconstruction. *Health Psychology: Official Journal of the Division of Health Psychology*, American Psychological Association, 34(4), 426-436.

Marshall C., & Kiemle, G. (2005). Breast reconstruction following cancer: Its impact on patients' and partners' sexual functioning. *Sexual and Relationship Therapy*, *20*(2), 155-177.

Marshall, C. E., Lengyel, C. O., & Menec, V. H. (2014). Body image and body work among older women: A review. *Ethnicity and Inequalities in Health and Social Care*, *7*(4), 198-210.

Matthews, H., Grunfeld, E. A., & Turner, A. (2017). The efficacy of interventions to improve psychosocial outcomes following surgical treatment for breast cancer: A systematic review and meta-analysis. *Psycho-oncology*, *26*(5), 593-607.

Moustakas, C. (1994). *Phenomenological research methods*. London: Sage.

National Health Service (NHS) (2018). Treatment: Breast cancer in women. Retrieved on the 18th November 2018 from: https://www.nhs.uk/conditions/breast-cancer/treatment/

National Institute for Health and Care Excellence (NICE) (2018). Breast cancer: NICE Pathways and NICE Guidelines: Retrieved on the 18th November 2018 from: https://www.nice.org.uk/guidance/conditions-and-diseases/cancer/breast-cancer#panel-pathways

Parton, C. M., Ussher, J. M., & Perz, J. (2015). Women's construction of embodiment and the abject sexual body after cancer. *Qualitative Health Research*, *26*(4), 490.

Perz, J., Ussher, J. M., & Gilbert, E. (2013). Constructions of sex and intimacy after cancer: Q methodology study of people with cancer, their partners, and health professionals. *BMC Cancer*, *13*, 270. Retrieved from http://www.biomedcentral.com/1471-2407/13/270

Pillai-Friedman, S., & Ashline, J. L. (2014). Women, breast cancer survivorship, sexual losses, and disenfranchised grief – a treatment model for clinicians. *Sexual and Relationship Therapy*, *29*(4), 436-453.

Raggio, G. A., Butryn, M. L., Arigo, D., Mikorski, R., & Palmer, S. C. (2014). Prevalence

and correlates of sexual morbidity in long-term breast cancer survivors. *Psychology & Health*, *29*(6), 632–650.

Reese, J. B., Porter, L., Bober, S. L., & Lapore, S. J. (2017). Effective patient provider communication about sexual concerns in breast cancer: A qualitative study. *Support Care Cancer*, *25*, 3199–3207.

Reich, M., Lesur, A., & Perdrizet-Chevallier, C. (2008). Depression, quality of life and breast cancer: A review of the literature. *Breast Cancer Res Treat*, *110*, 9–17.

Rodríguez-Prat, A., Monforte-Royo, C., Porta-Sales, J., Escribano, J., & Balaguer, A. (2016). Patient perspectives of dignity, autonomy and control at the end of life: Systematic review and meta-ethnography. *PLoS One, 11*(3), e0151435. Retrieved from http://doi.org/10.1371/journal.pone.0151435

Safarinejad, M. R., Shafiei, N., & Safarinejad, S. (2013). Quality of life and sexual functioning in young women with early-stage breast cancer 1 year after lumpectomy. *Psycho-Oncology*, *22*, 1242–1248.

Schover, L. R. (1991). The impact of breast cancer on sexuality, body image and intimate relationships. *Cancer Journal for Clinicians, 41,* 112–120.

Schover L. R., Fife, M., & Gershenson, D. M. (1989). Sexual dysfunction and treatment for early stage cervical cancer. *Cancer, 63*(1), 204-212.

Siegel, R., Naishadham, D., & Jemal, A. (2013). Cancer statistics, 2013. *CA: A Cancer Journal for Clinicians*, *63*(1), 11-30.

Slatman, J. (2014). Multiple dimensions of embodiment in medical practices. *Medicine Health Care and Philosophy*, *17*(4), 549-557.

Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology & Health*, *11*(2), 261–271.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research.* London & Los Angeles: SAGE.

Soothill, K., Morris, S. M., Harman, J., Francis, B., Thomas, C., & McIllmurray, M. B. (2001). The significant unmet needs of cancer patients: Probing psychosocial concerns. *Support Care Cancer*, *9*, 597–605.

Stead, M. L., Brown, J. M., Fallowfield, L., & Selby, P. (2003). Lack of communication between healthcare professionals and women with ovarian cancer about sexual issues. *British Journal of Cancer*, *88*(5), 666-671.

Tierney, K. D. (2008). Sexuality: A qualitative of life issue for cancer survivors. *Seminars in Oncology Nursing*, *24(2),* 71-79.

Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. Albany, NY: SUNY Press.

White, C. A., & Hood. C. (2014). Body image issues in oncology. In T. F. Cash & L. Smolak (Eds.), Body image: A handbook of science, practice, and *prevention* (pp. 333-340). New York: Guilford Publications.

Willig, C. (2013). *Introducing qualitative research in psychology* (3rd edition). Maidenhead: McGraw-Hill Education.

Wilmoth, M. C. (1998). Sexuality. In C. Burke (Ed.), *Psychosocial dimensions of oncology nursing care* (pp. 102-127). Pittsburgh (PA): Oncology Nursing Press.

World Cancer Research Fund (WCRF) (2018). Data on breast cancer statistics. Retrieved on the 10th June 2018 from: https://www.wcrf.org/int/cancer-facts-figures/data-specific-cancers/breast-cancer-statistics

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health, 15*(2), 215–228.

17. Appendices

17.1. *Psycho-Oncology Journal – Instruction for Authors*

Psycho-Oncology is concerned with the psychological, social, behavioural, and ethical aspects of cancer. This sub-speciality addresses the two major psychological dimensions of cancer: the psychological responses of patients to cancer at all stages of the disease, and that of their families and caretakers; and the psychological, behavioural and social factors that may influence the disease process. Psycho-oncology is an area of multi-disciplinary interest and has boundaries with the major specialities in oncology as well as psychiatry and psychology. This international journal is published twelve times a year and will consider contributions to research of clinical and theoretical interest.

Instructions for Authors

Manuscripts must be submitted as a Word or rtf file and should be written in English. The manuscript should be submitted in separate files: main text file; figures.

Original Paper

Original research papers should contain reports of new research findings that make a significant contribution to knowledge. Original papers should not exceed 4,000 words (including no more than four figures and/or tables) plus up to 40 references.

Text file

The text file should be presented in the following order:

(i) Title; (ii) a short running title of less than 70 characters; (iii) the full names of the authors; (iv) the author's institutional affiliations at which the work was carried out, (footnote for author's present address if different to where the work was carried out); (v) abstract; (vi) main text, (vii) acknowledgements, (viii) conflict of interest statement, (ix) references, (x) tables (each table complete with title and footnotes) (xi) figure legends, (xii) appendices (if relevant). Figures and supporting information should be supplied as separate files.

Title

The title should be a short informative title that contains the major key words.

Acknowledgements

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

Conflict of Interest Statement

You will be asked to disclose conflicts of interest during the submission process. The Conflict of Interest statement should be included within the main text file of your submission.

Abstract

Please provide an abstract of no more than 250 words. Abstracts should be structured according to the following headings: objective, methods, results and conclusions.

Keywords

Please provide up to 10 keywords and list them in alphabetical order. Please ensure that the keywords, cancer and oncology, are used for indexing purposes. Keywords should be taken from those recommended by the US National Library of Medicine's Medical Subject Headings (MeSH) browser list at https://www.nlm.nih.gov/mesh/.

Main text

Where possible, the text should be divided into the following sections: Background, Methods (including statistical methods), Results and Conclusions. All papers must include within the Conclusions section a paragraph explaining the study limitations (with subtitle "study limitations") and a paragraph explaining the clinical implications of the study (with subtitle

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"clinical implications"). A statement explicitly describing the ethical background to this study and any institutional or national ethical committee approval (including approval number) must be included within the manuscript. For clinical trial reports, the clinical trial registration number must be included within the manuscript.

References

All references should be numbered consecutively in order of appearance and should be as complete as possible. In text citations should be superscript numbers. Journal titles are abbreviated; abbreviations may be found in the following: MEDLINE, Index Medicus, or CalTech Library. Submissions are not required to reflect the precise reference formatting of the journal (use of italics, bold etc.), however it is important that all key elements of each reference are included. more information, please see the Vancouver Reference Style Guide.

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