

**SUBJECTIVE LIVED EXPERIENCES OF WOMEN WITH EARLY STAGE BREAST
CANCER IN CAPE TOWN**



BY

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Abstract

Breast cancer is a common cause of death among women worldwide. It has long been recognized as a major public health burden in high-income countries, however, the majority of cases are said to occur in low and middle-income countries, such as in South Africa. A breast cancer diagnosis and treatment heralds a series of frightening events and can be a traumatic experience. The manner in which women perceive and cope with their illness is predictive of emotional and physical health outcomes. It is thus imperative to explore the experiences of South African women, whose voices may have been silenced in the past. The purpose of my study was to explore the subjective lived experiences of women with early stage breast cancer undergoing treatment. The objectives of the study were to; explore the emotional experiences of women with early stage breast cancer undergoing treatment and secondly to explore how women perceive their bodies through their experience of early stage breast cancer while undergoing treatment. Phenomenology was used as the theoretical position conceptualising the study as well as the research design. This research study adopted a qualitative approach utilising in-depth face to face semi-structures interviews for collecting data. The participants were selected through purposive sampling and comprised six women aged between 30 and 40 who are undergoing treatment for early stage breast cancer. The data was analysed using interpretative phenomenological analysis. Emotions experienced were characterised by the shock of the diagnosis due to factors such as lack of family history and age. Participants reported positive changes and viewpoints which they gained through their breast cancer journey. Emotions were heightened during treatment due to the physical change experienced and the effects this had on family members and the general public. Furthermore, results indicated that participants, even though they discovered a new found love for life and for their wellbeing, neglected their emotional needs in order to protect family members. An additional reason for this neglect centered on the lack of understanding other individuals may have regarding the experiences of participants. Recommendations involves the encouragement of accessing counselling services and that interventions tailored to the needs of each patient especially according to age. All ethical considerations as stipulated by the University of the Western Cape were adhered to.

Declaration

I declare that “Subjective lived experiences of women with early stage breast cancer in Cape Town” is my own work, that it has not been submitted before for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged as complete references.

Nicole Scullard

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“For I know the plans I have for you, declares the Lord, plans for welfare and not for evil, to give you a future and a hope.”

Jeremiah 29:11

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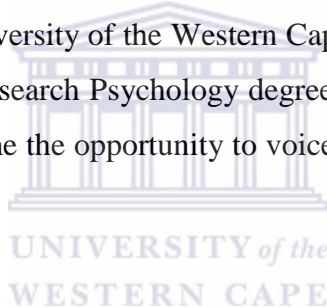


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CHAPTER ONE

INTRODUCTION

1.1. Introduction, Background and Rationale

The aim of this research study was to explore the subjective lived experiences of women undergoing treatment for early stage breast cancer. Within this research study, there were two objectives. The first objective was to explore the emotional experiences of women and secondly, to explore how women perceive their bodies through their experience of early stage breast cancer. Breast cancer is the second most commonly diagnosed cancer worldwide (World Health Organisation, 2012). Since 2008, the breast cancer incidence grew by more than 20% while mortality increased by 14%. It is thus the most common cause of cancer death among women with 522 000 deaths in 2012 and the most frequently diagnosed cancer among women in 140 of 184 countries worldwide (World Health Organisation, 2012). Kruger and Apffelstaedt (2007) state that the breast cancer burden in Africa is increasing. Similarly, according to the World Health Organization (2013), breast cancer is a leading cause of cancer death in the less developed countries of the world. This is partly because of a shift in lifestyles causing an increase in incidence, and partly because clinical advances to combat the disease are not reaching women living in these regions. Generally, worldwide trends show that rapid societal and economic changes as well as the shift towards lifestyles typical of industrialized countries leads to a rising burden of cancers associated with reproductive, dietary, and hormonal risk factors (World Health Organisation, 2013).

In keeping with global trends, breast cancer is the most common cancer among South African women. According to the National Cancer Registry (2005) breast cancer (excluding cancer of the skin) is the number one cancer among all females except for black¹ females where it is the number two cancer. It has been recorded that 1 in every 33 women in South Africa will develop breast cancer in their lifetime (National Cancer Registry, 2005 as cited in Herbst,

¹ The Population Registration Act of 1950 required that each inhabitant of South Africa be classified and registered in accordance with his or her racial characteristics as part of the system of apartheid (South African Demographic and Health Survey, 1998). The use of racial classifications such as white, black, coloured, Indian and Asian are viewed as socially constructed categories. I acknowledge that these categories are socially constructed entities that convey meanings about the historical and ongoing forms of social irregularities associated with race. I do not support the existence of these labels as innate; however, the use the term black is for practical reasons as these problematic labels continue to have a tremendous impact on social relations in South African, (Duncan, 2003; Seekings, 2008).

2013). With regards to age, a breast cancer diagnosis within South Africa, is found to be more prevalent between the ages of 40 and 69 (National Cancer Registry, 2005). The definition of a young woman in the field of breast oncology varies. The literature refers to women under the age of 35 or 45 as young while others refer to young women under the age of 50 as young. Kruger and Apffelstaedt (2007) state that the average age of diagnosis may be younger for women in developing countries than for women in developed countries. However, the prevalence of breast cancer in all age groups is rising (Adams *et al.*, 2011). Approximately 7% of women with breast cancer are diagnosed before the age of 40 years. Breast cancer accounts for more than 40% of all cancer in women in this age group (Anders *et al.*, 2009).

Experiences of living with breast cancer are said to vary by age but despite the prevalence of breast cancer in younger women, the specific key issues and concerns of this group are under researched (Adams *et al.*, 2011). From psychological and sociological perspectives, age has traditionally been used to define human stages of development. Early adulthood is generally accepted as spanning the time from late adolescence to the beginning of the perimenopausal years (Schuiling & Low, 2013). According to Erik Erikson, early adulthood is between the age of 20 and 39 (Swartz, de la Rey, Duncan & Townsend, 2008). This period is often referred to as the reproductive years, reflecting a societal valuing of women primarily for their reproductive capacities (Schuiling & Low, 2013). Additionally, Adams *et al.* (2011) notes that key developments associated with early adulthood include starting a career, entering long-term relationships, and the stabilisation of identities. The diagnosis of breast cancer impacts these developments in a woman's life by threatening the societal valuing of women given that breast cancer is viewed as an illness that changes one's sense of self and hence one's femininity and motherhood (Taha, Al-Qutob, Nyström, Wahlström & Berggren, 2012). Schuiling and Low (2013) further argue that women's changing roles have come at a cost to their health. It has been reported that balancing competing demands increases the stress levels of women which potentially results in engaging in unhealthy behaviours such as smoking, lack of exercise and poor nutrition (Schuiling & Low, 2013). Health problems that frequently occur during this stage of life include cardiac disease and cancer (Schuiling & Low, 2013).

Similarly to the views of Taha, *et al.* (2012) with regards to breast cancer being viewed as a threat to the societal valuing of women, Freund, McGuire and Podhurst (2003), relates to this

point when asking what it means to be sick. According to Freund et al. (2003), a tree's disease is similar to a human's disease in that it can recover or die however, unlike trees, humans must also grapple with the experiential aspects of sickness. Freund et al. (2003) explains that humans are capable of reflecting on themselves, their bodily conditions and their self-perceptions. This means that humans typically suffer, from disease but also from their experience of illness and the meaning that they and others attach to it. In addition, Freund et al. (2003) states that sickness tends to upset the social group too, as it is viewed as a breach of the ideals or norms of the society. This is because illness, according to Freund et al. (2003) represents a threat to the order and meanings by which people make sense of their lives and organize the routines of their everyday existence.

As highlighted above, the impact of breast cancer can be found globally, affecting all areas of one's life. More specifically, the body is at the centre of breast cancer experiences. It is however, important to understand what breast cancer is. Breast cancer is recognised as a disease in which malignant (cancerous) cells form in the tissues of the breast (National Breast Cancer Foundation). After receiving a breast cancer diagnosis, further tests are performed to determine how far the disease has progressed. This is referred to as breast cancer staging. According to the National Cancer Institute, the stage is based on the size of the tumour and whether the cancer has spread. Stages I, IIA, IIB, and IIIA are considered early-stage breast cancer and refer to cancers that may have spread to nearby lymph nodes but not too distant parts of the body. This definition of early stage breast cancer was utilised for this research study. After the stage of diagnosis is established, treatment options are explored.

Breast cancer treatment produces several different side effects impacting on the individual's wellbeing. Waters, Liu, Schootman and Jeffe, (2013) state that medical treatments and decisions should not be based solely on mortality outcomes, but should also consider the physical, emotional, and social impact of a cancer diagnosis and its treatments. These quality of life outcomes may be especially important for diseases with good prognoses, such as early-stage breast cancer, which offers patients the opportunity to live for many more years than diseases diagnosed at more advanced stages (Waters *et al.*, 2013). Receiving the initial breast cancer diagnosis leaves women psychologically vulnerable, experiencing various levels of distress (Campos, Besser, Ferreira & Blatt, 2012). Research conducted regarding the emotional experiences of breast cancer found that women were expected to express their emotions in a positive and cheerful way at all times. Women would experience a certain level

of distress; however they would not disclose their true emotional status. According to Van Oers and Schlebusch (2013) distress can compromise compliance with treatment and negatively affect prognosis and survival rates. Conversely, further studies found that women adopt a positive perspective through their experience of breast cancer. The emotional and psychological status forms an essential element of breast cancer treatment. In addition to emotional experiences, research has shown that one of the most difficult experiences women with breast cancer experience related to their body image and that women focused more on their body image than their health (Perreault & Bourbonnais, 2005). Hall (1997) states that the body is a site and source of subjectivity, identity and sense of self. Body changes as a result of breast surgery, bring into consciousness the connections between appearance, conceptions of how the self is seen by others and sense of self. This study therefore aims to provide women with a platform to voice their journey of breast cancer in relation to their physical and emotional experience.

Rationale.

Over the years a great deal of attention has been paid to the medical aspects of breast cancer, advanced breast cancer and on women who are older than the age of 40. A lack of qualitative research focusing not only on the experiences of women with breast cancer but more specifically early stage breast cancer among younger women is evident, especially in South Africa. In addition, it has been argued from a life-stage perspective that younger women have more of their life ahead of them and might therefore feel the impact of cancer more keenly (Adams *et al.*, 2011). Younger, premenopausal women seem to experience more distress, higher levels of depression, cope less well and report poorer quality of life than older women (Adams *et al.*, 2011). Qualitative research into the experiences of younger women is needed to add detail and depth to our knowledge of the meaning of breast cancer and to enable tailoring of interventions and to ensure the supportive care needs of different groups are met. Therefore this research study will aim to explore the experiences of women in early adulthood with early stage breast cancer using interpretative phenomenology as the theoretical lens. On a wider scale the Advocates for Breast Cancer believes that to significantly change breast cancer services for the majority of women in this country, management of this disease must be prioritised by national government. Involved organisations must combine their efforts with healthcare professionals to make it a matter of prime importance. Therefore health research needs to focus on the main issues around breast

health to ensure that the voices of women in all communities are heard. Given the rationale for my study it lends itself to the aim and objectives listed below.

1.2. Aim and Objectives of the Study

The aim of my study was to explore the subjective lived experiences of women aged between 30 and 40 years with early stage breast cancer undergoing treatment. The objectives of the study were to:

- Explore the subjective emotional experiences of women aged between 30 and 40 years with early stage breast cancer undergoing treatment.
- Explore how women aged between 30 and 40 years perceive their bodies through their experience of early stage breast cancer while undergoing treatment.

1.3. Chapter Organisation

Chapter one provides the reader with a detailed background, orientation, and context of the study. In addition, the aims of the study are discussed as well as the significance this study holds. Chapter two highlights the relevant themes pertaining to the research topic such as emotions experienced and the variations of distress, breast cancer and younger women, breast cancer in the context of beauty and sexuality and breast cancer treatment and body image. Furthermore, it introduces the theoretical framework. Chapter three details the method used to conduct the current study. It presents the methodological framework, research context, participants and sampling, data collection, procedure, data analysis, rigor, reflexivity and the ethical guidelines. Chapter four documents the key findings of the interviews conducted, and Chapter five provides an analysis and interpretation of the data using interpretative phenomenological analysis. Essentially, it highlights the true essence of the emotional and physical experiences of women while undergoing treatment. Chapter six concludes the thesis with a brief summary of the findings. In addition, the limitations of the study are discussed and future recommendations are made.

1.4. Conclusion

Breast cancer has long been recognized as a major public health burden in high-income countries, however, the majority of cases are said to occur in low and middle-income

countries, such as in South Africa, and it is expected that incidence rates will rise rapidly in these locations. It is important to gain understandings of the experiences of women within this context. This study will make a valuable contribution to a shortage of knowledge on the experiences of younger women with early stage breast cancer, especially in South Africa. Findings from the study will aid in giving a voice to previously silenced women shedding light on their experiences of their breast cancer journey. In this regard, findings could serve as a basis for various intervention strategies for younger women going through the treatment process for early stage breast cancer.



CHAPTER TWO

LITERATURE REVIEW

2.1. Introduction

The purpose of this chapter is to examine the extant literature and research related to breast cancer and the experiences thereof. This literature review is organized into nine main sections. The first section provides an overview of breast cancer followed by section two which explains the emotions experienced and the variations of women's distress. The uncertainty and fear experienced is discussed in the third section. The support, various responses from others as well as the silent experiences of emotion is presented in the fourth section. The literature has demonstrated that through this life changing journey a new love for life is discovered. This is covered in section five. Within this research study, the focus has been on younger women diagnosed with breast cancer, therefore section six focuses on breast cancer amongst younger women. In addition to focusing on younger women, the objectives of this study speaks to exploring body image, beauty, emotions and sexuality throughout the treatment process thus sections seven and eight presents the literature pertaining to these issues. Lastly, the ninth section explains the theoretical framework adopted in this study.

2.2. Breast Cancer Overview

Love and Lindsey (2010, p. 3) in their book, pose the question: "is there such a thing as a normal breast?" From a medical point of view their answer is yes, as a normal breast is one that produces milk. However, they argue that beyond this level the answer to the question they posed is no. This is due to the range of sizes and shapes of breasts. They note that most women have not seen other women's breast and that we all grow up with an image of ideal breasts, that is of equal proportion, reasonably large and firm, that permeates our society. Love and Lindsey (2010) state that few women fit this image and there is no reason why they should. As mentioned earlier, breast sizes differ. Breasts can be very large or very small and in most cases one breast is slighter larger than the other which has been noted as normal and common (Love & Lindsey, 2010). Breast size is genetically determined and depends chiefly

on the percentage of fat to other tissue in the breast. In order to have a deeper understanding of breast cancer, the exploration of the breast is important.

Breasts are made up of fat, supportive tissue and glandular tissue that contains lobes (Macmillan fact sheet, 2012). Cancer Council Australia (2014) explains that in women, breasts are made up of milk glands which consist of lobules and ducts. The lobules are where the milk is made while the ducts are the tubes that carry milk to the nipples. Furthermore, an area of breast tissue extends into the armpit (axilla). The armpits are said to contain a collection of lymph nodes which are part of the lymphatic system. The lymphatic system is part of the immune system and protects the body against disease and infection.

Cancer is recognised as a group of diseases that cause cells in the body to change and grow out of control (American Cancer Society, 2013). According to the American Cancer Society (2013), most types of cancer cells eventually form a lump or mass called a tumour, and are named after the part of the body where the tumour originates. Tumours are either benign or malignant. Benign tumours are not cancerous whereas malignant tumours are (Komen, 2014). The cells of a benign tumour do not invade nearby tissue or spread to other parts of the body. When these tumours are removed, most of the time they do not come back. Malignant tumours however can invade nearby tissue and spread to other parts of the body. A malignant tumour that develops in the breast is thus called breast cancer (Komen, 2014).

Breast cancer treatment options vary depending on the stage of the cancer. Garcia et al. (2007) explains that treatment takes into account the tumour size, stage, other clinical characteristics and patient preference. Treatment may involve surgery such as breast conserving therapy or lumpectomy, partial mastectomy and total mastectomy. Surgery can be followed or preceded by radiotherapy and/or chemotherapy. Further treatments for breast cancer include surgery, radiotherapy, chemotherapy, hormonal and targeted therapies. These therapies may be used alone or in combination depending on the stage of the disease. As noted earlier, early stage breast cancer includes stages I, IIA, IIB, and IIIA and refers to cancers that may have spread to nearby lymph nodes but not too distant parts of the body. According to the National Cancer Institute, treatment of early-stage breast cancer often involves more than one approach.

2.3. The Body

Bodies consists of various shapes, colours and sizes, are everywhere and are integral to our experience of being human (Kirk, 2002). The experience of our bodies therefore, constantly reminds us that being human is to be embodied. Corbin (2003) notes that over many years, one learns to understand the body's peculiarities, needs and language and that the changes that occurs has identity implications. Corbin saw the body as Merleau Ponty (1962), an embodiment of who we are. The body is the self's representative in the world. Similarly, Longo (2015) saw the body as ubiquitous in perceptual experience, and central to our sense of self and personal identity. He believed that our body is not ours, it is us and therefore how we mentally represent our body has profound implications for our sense of identity, self-esteem, and overall mental health such as through masculinities and femininities. Lorber and Martin (2007) speaks about the body in terms of masculinities and femininities. They note that members of society construct their bodies in ways that comply with accepted views of masculinity and femininity. Due to cultural and racial expectations of how a woman's body and a man's body should look, individuals try and shape and use their bodies to conform to these expectations. This point emphasises the influence that members of a society, not genes or biology determine the proper shape and usage of women's, men's, bodies. With regards to the representations of the breast in society and the media, the "normal female breast shape" is large, but not too large, firm and lifted. Women get targeted with advertisements for breast augmentation and/or breast lifts. These messages encourage women to judge their appearance against images that are culturally admired. Corbin (2003) highlights that the meaning of life derives from body. He states that it comes from being able to do, look and experience life in ways that the self comes to expect. He uses an example of his father having advanced Parkinson's disease wanting to die and states how devastating the emotional impact of how he reads himself and the meaning he gives to life in light of his disabilities. According to Corbin (2003), this was a reminder that suffering is more than physical in illness, it is also emotional because of the self which is affected by what happens to body. Corbin identifies that the body and self are caught in a fateful embrace. What happens to either affects the other. People rarely say, "My body had a heart attack" or "My body had cancer." They say, "I had a heart attack" or "I have cancer." (Corbin, 2003, p. 258).

Similarly, a South African study conducted by Fernandos, Papaikonomou & Nieuwoudt's (2006) aimed to provide a more complete understanding of personal suffering as experienced by women struggling with bodily issues. They found that the loss of control and identity formed the basis of the suffering experienced. Loss went beyond the removal of the breasts

and branches into the roles in the family, in the workplace and within the community. Emotions of sadness and depression was experienced which was mostly related to their view of themselves as defective and worthless. These feelings also related to feeling a loss of control in terms of their physical and emotional capabilities. Suffering according to Fernandos et al. (2006) involves feeling of loss, isolation, and emptiness in the physical, emotional and social domains. They state that all three contexts, although different, are interrelated with one another and cannot be separated and recommends that therapists and counsellors be more aware of their patient's suffering when therapy is sought, which entails an understanding of what the patient is experiencing on a physical, emotional, and social level.

2.4. Emotions Experienced and the Variations of Distress

A cancer diagnosis is threatening and confronts women with numerous stressors (Henselmans *et al*, 2010). Campos et al. (2012), states that breast cancer patients are at risk for affective disorders, such as anxiety and depression. They often report depression, anxiety, fear and anger at the time of diagnosis and during treatment (Clay 2013). Breast cancer has been conceptualised as a factor increasing the risk of clinical depression, with depression in turn leading to poor outcomes. According to Clay (2013), depression accompanying a chronic physical illness is associated with a higher death rate, longer time in hospital, and greater overall disability. Campos et al (2012) state that between 20% and 30% of cancer patients remain in a distressed state long after the initial diagnosis. A study was conducted by Henselmans et al. (2010), which explored the identification and prediction of distress trajectories in the first year after a breast cancer diagnosis. They found that emotional wellbeing is the most impaired in the first month after diagnosis and gradually improves thereafter. However the findings in their study showed that a large group of women with breast cancer reported no distress. These women were found to have high optimism, a strong support system and the least physical complaints. This study therefore sheds light on an important point; that not every woman has the same experience of breast cancer.

2.5. The Uncertainty and Fear Experienced

Fear has been documented throughout the literature with regards to breast cancer experiences. A study conducted by Perreault and Bourbonnais (2005), explored the suffering of women with breast cancer. In their findings, the psychological wellbeing of women was found to be based mainly on uncertainty. Being diagnosed with breast cancer raised the levels of anxiety

experienced mostly due to the unknown regarding their trajectory through life and the thoughts regarding death. Joulae, Joolae, Kadivar, and Hajibabae (2012), relates to the work of Perreault and Bourbonnais (2005) regarding the notion of uncertainty. Their study involved exploring Iranian women's lived experiences of breast cancer where they found that uncertainty about oneself was evident. Uncertainty about the future left women with low confidence and increased anxiety. Additionally, they found that fear was one of the emotions often experienced. Women experienced living in constant fear about death and constantly expecting tragic events to take place. Taha et al. (2012), in their research explored Jordanian women's views and perceptions about breast cancer and breast health. They highlighted the fear experienced in women after a breast cancer diagnosis. This fear related to body image, suffering, family life disruption and as mentioned above; death. Furthermore, intense fear for social stigma was evident. The word cancer itself was feared. Women would then try and hide their illness due to the fear of being socially stigmatised as the chances of marriage for daughters from mothers who has or had breast cancer will be hindered. In addition, because cancer attacks the breasts, which is considered a sensitive issue with regards to a woman's body, a breast cancer diagnosis is not disclosed. These results emphasize how prevalent fear is amongst women diagnosed with breast cancer. It also allows people to reflect on the point that as human beings peace is found in planning the future. However when diagnosed with an illness such as breast cancer, that peace and level of certainty they once had disappears.

2.6. Support, Emotional Dizziness and the Silent Experiences of Emotion

The roles of women and the way they are generally viewed in society impacts on their emotional experience while on their breast cancer journey. Family appears to be a source of support for most women throughout the disease. This is evident within the study conducted by Goldblatt, Cohen, Azaiza & Manassa (2013) who explored perceptions of breast cancer and its personal and familial implications, emotional reactions, and coping strategies in Israel. The majority of the women in their study, invested enormous efforts in concealing their fears, anxieties, and despair from their relatives. This was derived from the perception of the woman as the pillar of the home, perpetually strong, and available for family members at the expense of her own needs and difficulties. These results point out how women viewed their family as their biggest responsibility to the point of ignoring their own needs. Most of the women followed the principle that a mother and housewife should demonstrate competence, disguising signs of weakness, and suffering and thus only expressed their distress when alone. Thus, Goldblatt et al. (2013) notes that they lived simultaneously in two dimensions: in

the authentic (sad) interior and the happy and healthy exterior. Similarly, a qualitative study of patient, nurse and volunteer perspectives was conducted by Beatty et al. (2008) in order to identify the concerns and needs of women recently diagnosed with breast cancer. In their research, they found that family and friends could not handle the diagnosis of their loved one and therefore, their loved one had to “keep up a front” which resulted in decreased support and more distress (Beatty *et al.*, 2008, p. 338). Women were expected to always be strong and manage others. When women experienced levels of sadness, this was viewed as adopting a negative attitude towards a situation which was frowned upon. The role of women generally within society is highlighted in these studies and the impact it has on the experience of one’s breast cancer journey.

Joulaee et al. (2012) in their research; found that women with breast cancer were confused regarding the emotions of others and the emotional support they received through their experience of breast cancer. The reasons behind the emotional support from others were not clear. Women were found to question if the support received from friends and family members stemmed from an area of love or pity. In their study, Joulaee et al. (2012) noted that women experiencing breast cancer found that their family members would send mixed signals. They would be compassionate however; they would avoid spending a vast amount of time with their loved one who has breast cancer. Women with breast cancer were expected to be emotionally stable and therefore would not disclose any information to their family and friends. Banning and Tanzeem (2013) confirms this finding in their study which explored the psychological impact of breast cancer. They found that women suppressed their emotions in order to maintain the happiness of their children which in turn resulted in the lack of emotional and physical support experienced by these women. Again, the roles of women is shown to impact on their emotional wellbeing. Patel, Harcourt, Naqvi and Rumsey (2014) in their study on Black and South Asian women’s experiences of breast cancer, found that being well supported was imperative in the women’s experience. The amount of support they received from various sources helped participants deal with their diagnosis and treatments. The majority of the women spoke of receiving unlimited support from their family members, friends, work colleagues and support groups. They described this in terms of invaluable practical help with household chores, emotional support, moral support and informational support. On the other hand, women found that members of their community were unsupportive and would often make inappropriate remarks, which resulted in the women wanting to keep their cancer private and avoid such negativity. This finding is in line with the

works of Joulaee et al. (2012) and Banning and Tanzeem (2013). Although sources of support varied, family members and partners played a key role in supporting the majority of women.

2.7. A New Love for Life

Although a vast amount of literature highlights the emotional impact of breast cancer such as depression and anxiety, studies found that many women experience having a new love for life. Joulaee et al. (2012) in their study found that women believed that their diagnosis meant death. Conversely, certain women were more positive through their experience with breast cancer and thus found a new love for life and realised how valuable their health is. Clay (2013) found that women discovered a strong will to live and they wanted to live each day to the fullest. Women within the study first saw their diagnosis as a death sentence but then realised that their diagnosis meant that they need to live and seize every moment. They believed that they were not about to die but live. Horgan, Holcombe and Salmon's (2011) study explored the experience of positive change after a breast cancer diagnosis. Women's beliefs about what was important in life changed. Their breast cancer experience resulted in increased self-confidence to achieve their needs and goals and a lack of concern for what other people thought of them. Most women reflected upon the physical and emotional suffering they experienced. In doing so, they acknowledged the awfulness of the experience, stopped being positive, and gave themselves permission to admit to their pain and suffering. In reflecting on their suffering and experiencing new perspectives, many women began to alter their beliefs about what was important. Similarly, Patel et al. (2014) found that women already held strong religious beliefs which strengthened after their diagnosis. They felt that this was instrumental in helping them to understand and help them cope with their diagnosis. Participant's reflected on this life-threatening experience, and viewed it as having a new-found appreciation of life. Many viewed life as too short for them to worry about trivial things, and although it was second nature for them to think of family before themselves, they learned that it was also important to prioritise their own well-being. This stemmed from a commonly held belief that breast cancer was a result of being stressed led many women to try to avoid undue worry.

2.8. Breast Cancer and Younger Women

Anders et al. (2009) notes that although a diagnosis of breast cancer can be distressing to patients across all age groups, diagnosis at a young age presents a variety of unique psychosocial and emotional challenges, including, but not limited to, family and

relationships, body image, sexuality, and loss of fertility/premature menopause. Coyne and Borbasi (2009) states that there is less emphasis on breast cancer amongst women who are in the lower end of the age range. Their study explored the experience of breast cancer for women and describes their experience of coping with breast cancer treatment with the age of their participants ranging between the age of 29 and 43. Coyne and Borbasi (2009) reported that younger women experience greater physical and psychological difficulties as the stress of needing to be supportive of others particularly children, at a time of needing support oneself, is heightened for younger women. Within their study, results indicated that a diagnosis of breast cancer was a major shock which created a sense of disbelief. They found that participants asked the question why me? Although the experience of breast cancer was found to be unexpected and unbelievable, participants in their study reported that they had to be strong in order to maintain a sense of normality and calm for the family. Due to this desire to maintain the family's routine as normal, the participants in their study experienced an overwhelming sense of having to go through the treatment process alone. While women with children aimed to maintain a sense of normality coupled with fears about not surviving to see their children grow to adulthood (Spencer et al., 1999), women without children worried about infertility, or not being able to have children because of concerns about future cancer recurrence (Hassey Dow et al., 1994; Corney & Swinglehurs, 2014).

These concerns relate to life stage (Northouse, 1994), and highlight the stressors associated with being diagnosed with cancer at a young age. With regard to infertility and loss of choice about having children, women believed that these concerns were sometimes trivialized by health professionals, who felt that they should be more concerned about survival than loss of fertility. Women are advised to delay any pregnancy for a minimum of 2 years post treatment in case of cancer recurrence. However, those on hormone therapy may have to wait 5 years before pregnancy is advised. During this time, there will be an age-related decline in fertility as well as any impact on fertility due to chemotherapy administration, radiation, or drugs given. Corney & Swinglehurs (2014) in their research, explored in detail the fertility-related experiences of younger women, including the information they received, the fertility preservation options given, and the dilemmas they faced. Their research study highlights the fear of not being able to reproduce, the essence of womanhood for a vast number of women. Participants in their study reported that clinicians wanted to treat the cancer without delay as saving lives took priority over preserving fertility. They found that childless single women without partners were found to be particularly vulnerable. Finding a suitable partner was

made much more difficult after breast cancer, with changes in appearance, potential loss of fertility, and a reduced life expectancy. Those in their thirties felt that they had little time in which to find a partner and have a child. The results also highlighted variability in experience and fertility options given to participants. In some treatment centres, information, options, and emotional support were readily available. In others, the subject of fertility was dismissed as unimportant and discussions cut short. Participants thought that emotional support was important at all stages of treatment and recovery. They also had needs for both support and information. Corney and Swinglehurs, (2014) highlights the importance of education around these issues identified as well as the need for emotional support.

The importance of information and education which stems from research is thus vital. The Sixth Annual International Symposium in Mexico 2014, focused on young women and breast cancer. This was the first time the symposium focused almost entirely on young women. The reasons for this emphasis were presented by many national and global experts, such as Dr Susan Love, who presented evidence that breast cancer has become a leading cause of death among younger women in Mexico, and conveyed the benefits of early breast cancer detection and the need to create innovative solutions for care and survivorship support for this age group. They recognise that breast cancer amongst younger women is increasing in various countries. The symposium also emphasized breakthrough techniques developed to face short- and long-term challenges braved by patients with breast cancer. One of these, was emphasised by Corney and Swinglehurs, (2014) which is the need to preserve fertility in young women enduring chemotherapy. Up to 80% of women older than 40 underwent chemotherapy and up to 20% of women younger than 30 years of age will develop premature ovarian failure. Researchers also presented the dire need for comprehensive understanding of and suitable care for the patient's sexual health, since young women undergoing chemotherapy usually exhibit alterations to body image, self-esteem, premature menopause, and dyspareunia, among others.

2.9. Breast Cancer in the Context of Beauty and Sexuality

Taha et al. (2012), highlights the understanding that women with breast cancer have regarding their bodies. Women, in their study, viewed breast cancer as something that deprives women of their femininity and motherhood. Women stated that regardless of how their husband or family viewed them, they always felt less womanly. These women going through the lived experience of breast cancer cared to a large extent about beauty and firmly believed that breasts are vital to being beautiful. A study conducted in South Africa by

Mdondolo, de Villiers and Ehlers (2004) explored the cultural factors associated with the management of breast lumps amongst Xhosa women in South Africa. Results indicated that a level of shame was experienced by participants as stigma is attached to breast cancer and a fear of losing their femininity, their intimate relationships and their appearance. Not informing anyone of a breast lump was due to the meanings attached to the female breast. It has significance in terms of femininity, intimacy, breastfeeding and thus the thought of losing a breast was devastating to Xhosa women. Similarly, these aspects are highlighted in a study by Mulder (2012) which explores experiences encountered during the waiting period, as well as the impact of breast cancer and its treatment on feminine identity in the South African context. The thought of losing a breast and how this would appear while wearing a dress, especially in the work environment, was agonising. A vast amount of women in the study could not look at themselves. Similarly, Perreault and Bourbonnais (2005) found that one of the most difficult experiences was related to their body image. Women were found to rearrange their homes in order not to see their scars reflected in the mirror. Gilbert, Ussher & Perz, (2010), highlight the impact of breast cancer on women's sexuality. In their review of research on breast cancer and sexuality from the year 1998 to 2010, they state that women with breast cancer experience a range of serious negative emotional changes as a result of disturbances to their sexuality, including the fear of loss of fertility, negative body image, feelings of sexual unattractiveness and loss of femininity. Breasts are often positioned as such a significant part of women's sense of self that for those who undergo a mastectomy having one breast is associated with being half a woman (Gilbert *et al.*, 2010). Research also shows that the strongest consistent predictor of sexual problems after breast cancer is lowered perceived sexual attractiveness (Gilbert *et al.*, 2010). Women who have a poor body image after breast cancer have lower rates of sexual satisfaction and are more dissatisfied with their sexual relationship than those with a positive body image (Gilbert *et al.*, 2010). Similarly, McCann *et al.* (2010) in their study on the transitional experiences of women with breast cancer within the first year following diagnosis found that changes in physical appearance can impact on a woman's sexuality following the diagnosis of breast cancer. Although women accepted that they would potentially experience a change in their appearance as a consequence of surgery and treatment, gaining acceptance from other people of this altered body state when it actually happened was critical. They found that women spoke about the need to feel accepted sexually. They found that the transition between health, illness and living with cancer can often be compounded by challenges and threats to one's identity and self. Women's perceptions of their physical appearance were found to be located and shaped

in a social context. The reactions of those around them were a central part of how women perceived themselves and at times, positive reactions from those around them proved difficult to contend with. McCann et al. (2010) states that for many women within the study, the topic of hair loss and its effect on identity and self-esteem was a regular and recurring feature, often more than breast loss itself, suggesting that loss of hair is a more visible and societal branding associated with being a person with cancer.

Thomas-MacLean & Miedema (2012) applied a material-discursive lens to examine the social and material experiences of women who have undergone breast cancer treatment and have developed the chronic condition of breast cancer-related lymphedema (BCRL). Thomas-MacLean & Miedema (2012) highlight the argument put forward by Adrienne Asch and Michelle Fine that people who have had cancer may be impaired socially as a result of changes to their appearance. This provides a foundation for understanding what it means to be embodied within a particular social context. Participants expressed concerns about the reactions of others to their altered appearances, experiences of BCRL may be interpreted as a form of disability

2.10. Breast Cancer Treatment, Body Image and the Emotions Involved

The experiences women had while receiving treatment highlighted their views regarding their body image. Moreira and Canavarro (2010) conducted a study about the body image and psychosocial adjustment of breast cancer patients during the course of the disease. In their study, they found that there was a predictive role of the type of surgery on body image. Specifically, having a mastectomy proved to be associated with higher body shame and less satisfaction with appearance whereas breast conserving surgery was associated with a better body image, because of their less mutilating effects. Rubin and Tanenbaum (2011) notes that women today live in a half changed world where breast cancer awareness is highlighted but also the concealment of one's illness. They state that this is not surprising that women are encouraged to cover up the effects that cancer has on their body, particularly the breast as breast loss is typically viewed through a male identified lens. In their research they found that breast reconstruction was a natural step in treatment following a mastectomy. Rubin and Tanenbaum (2011) highlights that breast cancer is more often portrayed as a cosmetic crisis rather than a major health crisis. Breast cancer is viewed as a threat to the construction of women's beauty and thus to the female identity. As mentioned above, when considering breast cancer treatment, the focus tends to be on the physical distress and change in

appearance. Women treated with chemotherapy report distressing side effects of altered cognitive functioning affecting their ability to focus, think clearly and perform daily tasks. Berman and Askren (2014) notes that the distressing nature of a cancer diagnoses has been recognized by health care providers however its neurocognitive effect has been ignored. They note that one factor that may affect cognition is the psychological distress surrounding diagnosis and treatment for cancer. Their study is the first to examine whether pre-treatment worry contributes to cognitive deficits observed in women before treatment for early stage breast cancer. Results indicated that self-reported worry was significantly associated with objective performance on a test of verbal working memory and perceived cognitive functioning in daily life. In addition to the effects of worry that characterize the entire sample, this study found a significant group difference in self-reported worry, with women awaiting chemotherapy reporting higher levels of worry than those awaiting radiation. This pre-treatment effect is an important clinical finding. The anticipation of chemotherapy and its toxic side effects may be inherently more worrisome than facing the need for local radiation therapy alone. Women have to face a longer course of treatment with the possibility of distressing side effects associated with chemotherapy. This finding is thus in line with the findings discussed above in the research conducted by Moreira and Canavarro (2010); and Rubin and Tanenbaum (2011). Berman and Askren's (2014) research highlights that the implications for treatment are important because worry can compromise cognitive function before any treatment, potentially making women more vulnerable to possible cognitive side effects due to chemotherapy and radiation. Overall these findings implicate worry as an important factor to target for early intervention in women being treated for breast cancer. Therefore therapeutic interventions to treat worry should be initiated before treatment, particularly for women awaiting chemotherapy.

Although Berman and Askren (2014) found that the levels of worry was lower for radiation, it was evident that that worry existed. Sherminie and Cottrel (2014), in their study explored the experiences of women with breast cancer undergoing radiation therapy. They found that participants were very fearful of the unknown and the effects that radiation could have on their bodies. There were many unanswered questions which in turn reflect that women craved more knowledge. Emotions rose due to lack of knowledge of treatment. Patients undergoing radiation therapy treatment commonly experience a range of adverse effects including treatment-related fears. Their study points out, as highlighted by Berman and Askren (2014), that, to deliver a comfortable, quality treatment for their patients, health care professionals

should strive to alleviate these fears, anxiety, and lack of knowledge regarding treatment. It is thus vital to provide a platform where women can share their experiences to provide insight to their day to day realities. Phenomenology, the theoretical framework used to conceptualise this study, emphasises the importance of personal perspective and is viewed as a powerful tool for understanding subjective experience, and gaining insights into people's motivations, actions, needs and concerns.

2.11. Theoretical Framework

The term phenomenology has been widely used and therefore there has been much disagreement about its meaning. Phenomenology has been conceptualised as a philosophy, as a research method and even as an all-encompassing perspective from which qualitative research is sourced (Ehrich, 2005). Phenomenology is a philosophic attitude and research approach (Flood, 2010). As the name suggests, phenomenology is the study of phenomena, their nature and their meanings (McPhail, 1995). Phenomenological approaches are based in a paradigm of personal knowledge and subjectivity, and emphasise the importance of personal perspective and interpretation (Lester, 1999). As such they are powerful for understanding subjective experiences, and gaining insights into people's motivations and actions. In order to explore the subjective lived experiences of women with early stage breast cancer, an interpretative phenomenological theoretical position was used to conceptualise this research study. Interpretative phenomenology based on hermeneutics goes beyond description of core concepts and essences to look for meanings embedded in common practices. In interpretive phenomenology, it is the interpretation of the narratives provided by participants in relation to various contexts that is foundational. Interpretative phenomenology allows one to explore and consider the context of participants to fully understand the worlds of these women. Participants in this study are younger women with early stage breast cancer. Dunn and Steginga (2000) states that from a developmental perspective, younger women with breast cancer experience the stress of cancer concurrent to the multiple stressors associated with the early stage of the family life cycle. They may also experience more disruption to self-image and sexuality. Importantly they note that this aspect of young women's experience of breast cancer may be a consequence of being more vulnerable to social pressure to conform to stereotypes of youth and beauty. Notably, Heidegger (1962) asserted that humans are embedded in their world to such an extent that subjective experiences are inextricably linked with social, cultural and political contexts (Lopez & Willis, 2004). While individuals are free to make choices, their freedom is not absolute, it is

circumscribed by the specific conditions of their daily lives. Lopez and Willis (2004) states that there is no one true meaning produced by any interpretive study, but the meanings that are stated in the research findings must be logical and plausible within the study framework, and must reflect the realities of the study participants.

CHAPTER THREE METHODOLOGY

3.1. Introduction

The following discussion highlights the methodology that was used in conducting this study. The research design, participants, method of data collection, data collection procedure, data analysis and ethical considerations will be explained. The methodology of this research study stemmed from the aims and objectives of this study stated earlier. In recent years, approaches to research on breast cancer acknowledged the importance of exploring the experiences of illness in order to inform interventions and breast cancer policy within South Africa. The quantitative research on prevention, treatment and other important medical advancements are vital in the area of breast cancer. However, exploring the issue qualitatively adds to the body of knowledge, shedding light on important issues that women within the South African context face. Accordingly, the method utilised in this study resonates with the sentiment above, and is the focus of this chapter

3.2. Research Design

In this exploratory design, qualitative methods was employed with the purpose of gaining a comprehensive understanding of women's subjective lived experiences of early stage breast cancer. Qualitative research is best suited for gathering in-depth understandings of questions

dealing with how rather than why questions (Becker, 1998). Due to the nature of the aims and objectives of this research study, phenomenology was adopted as the philosophical viewpoint as well as the research approach. Phenomenological methods are particularly effective at bringing to the fore the experiences and perceptions of individuals from their own perspectives (Lester, 1999). It involves gathering in-depth information and perceptions through inductive, qualitative methods such as interviews (Lester, 1999). Within this phenomenological study, interpretative phenomenological analysis was utilized in this study.

3.3. Participants

The method of selection which was used in conducting this study is a type of non-probability sampling namely; purposive and snowball sampling. Purposive sampling was set out as the method of selection, however due to sampling restraints, snowball sampling was employed. The participants of this study were six women who are in treatment for early stage breast cancer, who appeared to be middle class. Smith, Flowers and Larkin (2010) suggests that the number of participants range between three and six when one conducts a research study using interpretative phenomenological analysis. As mentioned earlier, the definition of a young woman in the field of breast oncology varies however, for the purpose of this research study,

Demographics	Ruth	Sandy	Penelope	Gaby	Amy	Mary
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participants were between the ages of 30 and 40. Issues of race and language are important to consider within the South African context. My selection criteria did not exclude anyone based on race, however participants were fluent in English, even though English was not the first language for certain participants. The interviews were therefore conducted in English.

3.3.1. Brief particulars of women interviewed.

The following section presents a brief description of each participant. Pseudonyms have been used to safeguard the confidentiality of all participants. The table below displays the age, home language, marital status, the number of children and the stage of cancer of each participant. All research participants were in treatment for early stage breast cancer at the time of interviews. Certain interviews thus had to be rescheduled to ensure the wellbeing of participants. The youngest participant was 32 and the oldest 40. One third of participants were married, another single and the last third, divorced. Four out of the six participants had children. These particulars are displayed in the table below:

Age	40	39	32	40	38	36
Home language	English	English	Xhosa	English	Afrikaans	English
Marital status	Married	Married	Single	Divorced	Divorced	Single
No. of children	2	2	0	1	2	0
Stage of cancer	II	III	II	I	I	I

Table 1: Demographics of participants.

3.4. Data Collection

Interviewing is viewed as one of the most powerful and common ways in which we try to understand human beings and includes a wide variety of forms. For the purpose of this research study, in-depth, face-to-face interviews were utilised to collect the data. In-depth, face-to-face interviews are directed by a semi-structured interview schedule. According to Moore (2000), semi-structured interviews are like a midpoint between the formality of a structured interview and the flexibility of a depth interview. Smith et al. (2009, p. 57), states that IPA “aims to design data collection events which elicit detailed stories, thoughts and feelings from participants”. They state that semi structured interviews are the preferred means for collecting such data. The interview schedule (see appendix D) was guided by the literature reviewed and based on exploring the emotional experiences as well as the perceptions women have regarding their bodies through their experience of early stage breast cancer. When using semi structured interviews with interpretative phenomenological analysis, Smith et al. (2009) suggests using an interview schedule with between six and ten open-ended questions along with possible prompts. Seven open-ended questions was utilised within this research study.

3.5. Procedure

I did not foresee a problem in obtaining participants for this study, given the inclusion criteria being, women between the age of 30 and 40 years diagnosed with early stage breast cancer. Accessing participants within this research study has proven to be challenging due to the age range specified above and the access being denied from private oncology units due to ethical reasons as certain patients were on clinical trials. Other organisations and support groups

were then approached, however, the age range continually proved to be challenging. Social media was then used to assist in this regard, which proved to be successful. A call for women matching the profile needed for this study was posted on Facebook, a social media platform. Women would then respond by stating that they know a possible candidate which I followed up on. The majority of the responses gained proved to be unsuccessful due to the age range. Recruiting participants involved a continuous back and forth process whereby a call would be put out through family, friends and social media. Through this process, a sample of six participants were recruited.

When meeting with participants at a place and time chosen by them, the establishment of rapport was vital due to the sensitive nature of the study. After I introduced myself, I proceeded to thank the participant for participating in the study. I engaged participants in polite conversation striving to assist with participants feeling comfortable. I then presented them with an information sheet (see Appendix A) while explaining to participants the nature and objectives of the research. Issues of confidentiality as well as all ethical measures were discussed and participants gave their written consent to participate (see Appendix B). Demographic information gained from participants assisted in getting to know each participant and asking for an elaboration on certain questions such as: “I see that you were diagnosed last year, tell me more about that day and the events leading up to that” which contributed to the development of rapport.

The duration of the interviews was approximately one hour. Certain participants needed more probing more than others especially when reflecting on emotions. One question that was particularly thought provoking and took participants longer to respond to related to how they see themselves. The tone of the interviews varied from person to person, however, each participant, through their responses, found it particularly difficult to reflect on their emotions instead of those of others. Interviews were audio-recorded and then transcribed verbatim. The audio-files were kept under lock and key and transcriptions were stored on a password protected computer

3.6. Data Analysis

The data collected was analysed using interpretative phenomenological analysis. Pietkiewicz and Smith (2014) states that the primary goal of IPA researchers is to investigate how individuals make sense of their experiences. He notes that it is assumed that people are self-interpreting beings which means that they are actively engaged in interpreting the events,

objects, and people in their lives. To examine this process, IPA draws upon the fundamental principles of phenomenology, hermeneutics, and idiography (Pietkiewicz & Smith, 2014). Through this results and discussion chapters to follow, I aimed to represent and capture each key position through developing descriptions of the essence of experiences, interpreting these descriptions and providing an intensive and detailed analysis of the accounts produced by a comparatively small number of participants. Heidegger furthered these above sentiments in that he was concerned with the ontological question of existence itself. According to hermeneutics one needs to comprehend the mind-set of a person and their language which mediates one's experiences of the world, in order to translate his or her message (Freeman, 2008). Thus, IPA researchers attempt to understand what it is like to stand in the shoes of their subject (although recognizing this is never completely possible) and, through interpretative activity, make meaning comprehensible by translating it (just like the mythological Hermes translated the gods' messages to humans). This means that the IPA study is a dynamic process with the active role of the researcher who influences the extent to which they get access to the participant's experience and how, through interpretative activity, they make sense of the subject's personal world. The analytical process in IPA is often described in terms of a double hermeneutic or dual interpretation. Interpretative phenomenological analysis is an interpretative endeavour and is viewed as being informed by hermeneutics (Smith *et al.*, 2009). As a researcher using interpretative phenomenological analysis, one becomes involved in a double hermeneutic which refers to the researcher trying to make sense of the participant trying to make sense of what is happening to them (Smith *et al.*, 2009). In other words, IPA researchers try to understand what an experience is like from the participant's perspective. Yet, at the same time, they try to formulate critical questions referring to the material.

Each individual case was explored first, before analysing the next case, until all cases in the study was explored. A six step analytical process established by Smith *et al.* (2009) was followed after the transcription of all data to conduct a thorough analysis of the data. Step one involved reading and re-reading the data in order to focus on that participant and to become immersed in the data. The second step involved an initial level of analysis which examines the semantic content and language use on an exploratory level. In step three, emergent themes were developed. Step four involved searching for connections across emergent themes. This step involved mapping how one thought the themes fit together. Step five involved moving to the next participant and repeating the process. The last step in interpretative

phenomenological analysis according to Smith et al. (2009) involved the exploration of patterns across cases. Within phenomenology, in order to discover meanings in the data, one needs an attitude open enough to let unexpected meanings emerge (Chan, Fung & Chien, 2013). This takes place through the fundamental methodology of bracketing. Chan et al. (2013), states that bracketing requires deliberate putting aside one's own belief about the phenomenon under investigation or what one already knows about the subject prior to and throughout the phenomenological investigation. The researcher is the primary instrument for data collection and analysis in qualitative research through which findings are mediated. Chan et al. (2013) highlights an important point; if the researchers are unaware of their own preconceptions and beliefs, it is impossible for them to put these issues aside. Therefore, they state that, the ability to be aware of one's own values, interests, perceptions and thoughts becomes a prerequisite before we can set aside the things that influence the research process. Throughout this study, more so during data collection was bracketing employed through means of a reflective journal

3.7. Rigor

Guba proposes four criteria that he believes should be considered by qualitative researchers in pursuit of a trustworthy study namely; credibility, transferability, dependability and confirmability (Shenton, 2004). To ensure credibility, thick descriptions of the phenomenon were provided and rapport with participants before the interviews was established to ensure a relationship of trust. Debriefing with the supervisor of this research study as well as reflective commentary was utilised by means of a self-reflective journal from the inception to the completion of the study. The emergence of any assumptions or biases that may come to the fore can then be examined and set aside to a certain extent. This took place through bracketing; a methodological device of phenomenological inquiry. To enhance transferability, detailed information regarding the nature of results and context was provided. With regards to dependability, the process of this research study was reported in detail to allow other researchers to repeat the study and achieve similar results. Confirmability ensures that the findings are the result of the experiences and ideas of the participants, rather than that of the researcher (Shenton, 2004). This relates to credibility and making sure that the interpretations made is an accurate reflection of women's experience and reflecting on the impact that, I as the researcher, may have had on the research process.

3.8. Ethics

The ethical considerations of the study fall under those stipulated by the University of the Western Cape. The research was conducted ethically, in that the participants were informed of the aims and goals of the research process before actually participating. This was substantiated by a written consent from the participants (see appendix B). This consent form explained that the participation of the participant is voluntary and that they may withdraw at any time. Additionally, it assured the participant that the data collected was kept confidential and their identity was not be exposed. The digital equipment and verbatim transcripts were kept safe and stored in a place to which only I, the researcher, had access to. Additionally, the data was saved in password-protected computer files. To maintain the anonymity of participants, pseudonyms were used when writing up the results obtained. Considerations of the emotional wellbeing of the participants are important. Due to the nature of the research, debriefing was necessary. Participants revealed that they were not accessing any counselling services and had no desire to do so. However, the option of accessing the National Counselling Call Centre was provided to them. This allows participants to access free confidential counselling 24 hours a day.

3.9. Reflexivity

Reflexivity has been an important part in the evolution of qualitative research (Finlay & Gough, 2003). Interpretative phenomenology holds the view that it is impossible to rid the mind of the background of understandings that has led the researcher to consider a topic worthy of research in the first place (Lopez & Willis, 2004). The impact of my views, passions and beliefs is evident in my research question and has been throughout the conceptualisation process. My passion for research focusing of women and their gendered experiences has steered me in this direction of women's health and voicing their experiences. My own experience of the medical world as well as the impact that breast cancer has had on my family and friends contributed to the birth of this area of research.

As I reflected through this process, I believe that being a woman myself allowed participants to feel comfortable with sharing their lived experiences. The differences we share such as our background and age which I suspected may have affected the interaction between myself, being the researcher and the participants however, it did not appear to have affected the interaction in any negative way. Participants according to their verbal and non-verbal cues appeared comfortable to be able to allow me into their world.

Prior to the study, I completed an internship as a substance abuse counsellor. I believe this previous training allowed me to actively listen to participants and equipped me with the skills needed to be sensitive to what may emerge and to be able to display a level of empathy throughout the data collection process. Furthermore, during the data collection process I remained in therapy which assisted me in processing any feelings that may hinder the process. After each interview I felt honoured that these women allowed me into their world. Their courage inspired me in many ways. I was overcome with the desire to help women and by completing this research study is one way in which I can accomplish this goal.

Participants noted that no one will understand their journey only individuals diagnosed with breast cancer. This important point may have impacted on the interview process, in the way in which they spoke as well as the responses gained from participants. Additionally, this study is based within a phenomenological framework which aims to present the realities of participants, to understand their world. Their world, a world where no one understands except those diagnosed with breast cancer. Even though certain participants noted that people who do not have a diagnosis of breast cancer would not understand their experience, they willingly participated in this study wanting to voice their stories. Smith (1996) recognizes that the access to experience is both partial and complex. Larkin, Watts and Clifton (2006) explains that that analytic process cannot ever achieve a genuinely first person account. The account is always constructed by participant and researcher. Through a coherent third person psychology informed description and interpretation, I tried to get as close to the participants' view as possible. This leads me to the next chapter, the worlds of my participants, the results section.



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CHAPTER FOUR

FINDINGS

4.1. Introduction

The aim of this research study was to explore the subjective lived experiences of women undergoing treatment for early stage breast cancer. The following chapter presents the findings of the transcribed interviews utilising interpretative phenomenological analysis. Larkin, Watts and Clifton (2006) notes that providing a first-order analysis undermines the potential of IPA to properly explore, understand and communicate the experiences and viewpoints offered by its participants. According to Larkin et al. (2006) two aims should be used to approach ones data. The first aim is to try and understand the participants' world and to describe what it is like. The second aim is to develop a more overtly interpretative analysis which positions the initial description in relation to a wider social, cultural context. This

provides a critical and conceptual commentary upon the participants' personal sense making activities. This allows one to deal with the data in a more speculative fashion in that one thinks about what it means for the participants to have made these claims and to have expressed these feelings and concerns in this particular situation. Braun and Clarke (2013) states that it is usual to separate out the results and discussion in an IPA report. The results section according to Braun and Clarke (2013) should provide a close reading of the participants' experiences without reference to the wider literature. In the discussion section you should consider how your results relate to wider literature and how existing literature can elucidate your results. This will therefore be the structure of the next two chapters of this study. The themes that emerged from the analysis of each transcript were compared in order to present the dominant stories of the participants' experiences. This revealed both shared and contrasting experiences. Five super-ordinate themes namely: *receiving the diagnosis, effects of treatment, silent suffering, coping strategies* and *a turning point*, encapsulating the participants' emotional and physical experiences of breast cancer were identified.

4.2. Receiving the Diagnosis

The diagnosis of an illness elicits various responses from individuals. This theme; "receiving the diagnosis" presents the emotions experienced by all participants regarding their reactions to receiving a breast cancer diagnosis. This theme consists of three subordinate themes namely; Unexpected. Shock. Fear, Is this really happening to me? And Yes me and lastly, betrayal by the body

4.2.1. Unexpected. Shock. Fear.

These three words encapsulate this subordinate theme. The diagnosis of breast cancer proved to be an unexpected one and was also characterised by shock and fear. Various aspects influenced these emotions. This is illustrated in the extracts below:

I was shocked to my core, as cancer is the last disease I ever thought of. Also there is no family history about it. I thought of death, and my son. (Gaby)

Above Gaby expresses the level of shock she experienced which she articulated by stating "shocked to my core" Cancer was not something she thought of, her response above implies that she may have thought of other illnesses but not cancer. The unexpected nature was influenced by the fact that there was no family history of cancer. It also illustrates that her first thoughts were about death and as a mother, the wellbeing of her son. The influence of

no family history on the level of shock experienced by Gaby was evident in the responses from other participants as well.

I was scared, scared.. (pause).... I went to the doctor, had myself checked out and she said ya she thinks it's nothing. I then left it and forgot about it. But then a week later the results came and she said it's looking suspicious, I should see a breast specialist. I went to see the specialist and she only felt it and told me she suspects it is cancerous. I was so shocked. (Mary)

I think because I'm young and I had no history, no family history. (Mary)

Mary states that she felt scared. In her response she paused and repeats that she was scared. This could indicate a moment of reflection which may have been difficult due to the unknown, hence the pause. She then provides an account of a lived experience which ultimately determined her level of shock. After seeing the doctor, accepting her opinion regarding the lump, Mary forgot about the lump. Mary trusted the doctor's opinion and therefore never thought much about her lump. When asked about why she may think the doctor may have informed her that it is nothing serious, Mary noted that her age and no family history may be the reasons why the doctor didn't suspect anything. A breast cancer diagnosis is expected amongst older women with a family history of breast cancer. Penelope went through a similar experience to that of Mary. This is presented below:

Ohk so, um...I found a lump and then, I work in theatre, I always find that you can get a doctor and just ask them to check, so one of the doctors checked for me and then she said ok we will send it away, that was the Wednesday, she said she will write there urgently. She said she doesn't think that it's serious because of my age. She didn't think much of it. We received the results the Friday and she said its cancer cells. So she tells me that they just going to make sure it's really really there. So I went to hospital, they checked and told me that it is cancer from there I asked them what's the solution for it. (Penelope)

The doctor that Penelope consulted did not expect anything serious due to her age. Her immediate response to finding out that she has breast cancer was about finding the solution instead of fixating on the problem. She continues however the first sentence is not personalised in her use of "you" instead of I.

Imagine you don't have any family here, you scared to tell your parents that they found something. I mean there is no history at home of breast cancer or any cancer so ya I told them later on. (Penelope)

Penelope, like the other participants above, refers to the fact that there was no family history of any cancer and explains the events subsequent to receiving her diagnosis as well as how rapidly everything happened. Ruth, however, provides some insight regarding the reasons why she failed to suspect breast cancer.

I was absolutely shattered, it's not something that I expected, I um... knew that I had a lump in my breast long time ago but having two children and having breast fed both kids I just assumed that it was either a fibroid gland or a lump but not cancer at all. I have no cancer in my family, there is no history of cancer, no great grandparents or anything like that. I am actually the first person to be diagnosed with cancer in my family. (Ruth).

Being a mother and having breast fed her children took away any suspicion of breast cancer for Ruth. She also notes how the diagnosis affected her emotionally by stating that she was “absolutely shattered” which indicates how broken and hurt she felt emotionally. As with the other participants above, Ruth refers to the family history and notes that there is no family history of breast cancer and that she is the only one in her family diagnosed with the illness. Her use of the word “actually” is used to emphasise how surprising this diagnosis is for her.

4.2.2. Is this really happening to me?

In addition to the shock and fear experienced by the participants above, certain participants wondered “why me?” The extracts below display these findings.

You don't believe that it will happen to you because I mean generally everything happens to other people you know, it doesn't happen to you and based on that, when the call came, I was at work, the doctor actually called me and said I am very sorry but it is cancer. I broke down at the office, I just burst into tears and cried and cried and cried and I couldn't believe that it had actually happened to me. (Ruth)

Ruth illustrates her disbelief regarding her diagnosis. She starts off by reflecting in the third person however she provides us with an experience where she received the news regarding her diagnosis. Additionally her emotional state is noted as well as her surprise regarding her diagnosis which is displayed through the use of the word actually. She could not believe that it was happening to her per se. It appears to be easier to believe that it can happen to other people in general. Additionally, when asked about treatment, Ruth reflected for the second time, on her feelings of disbelief that she now has breast cancer.

That's a difficult question because, um... there are days, I mean funny enough (giggle).. I had two or three days where I actually just like burst into tears where I said I can't believe this is happening to me, I can't believe I am going through this um. (Ruth)

In Ruth's response above, she could imagine someone else being diagnosed with breast cancer but not her. This thought of it happening to other individuals is also evident in the responses received from the participants below. Additionally, Mary reflected on the dilemma of informing her family as had Penelope above. She also illuminated the thought of it happening to others as her friend had cancer but the thought of her having breast cancer was unimaginable. Optimistic bias was therefore evident. Below, a further two participants questioned why they were diagnosed with breast cancer.

Well, (pause) you feel like (pause)...why you, why particularly you and not someone else. (Sandy)

I thought maybe someone else but not me. I had a friend who died from prostate cancer. I thought to myself how will he phone his parents who are not in the country with the news that he has cancer and now I find myself in that situation. I never would have thought it would happen to me. I mean how do you call your parents and tell them I have cancer. And now a few years later I have cancer, I'm in the same situation somehow. I never would have thought that it would happen to me. (Mary)

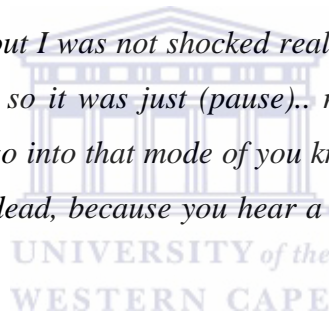
All three participants who wondered why they were diagnosed with breast cancer referred to other people being diagnosed with the illness. Participants either questioned why someone

else was not diagnosed with breast cancer or they had the expectation that it may happen to others but not them. Mary mentions that she had a friend who passed away due to prostate cancer. She wondered how he would inform his parents of his diagnosis. She only wondered about informing family members and how difficult that may be. That was a concern for her friend as well as for herself. Even though cancer hit so close to home in that her friend passed away from the illness, she never considered the possibility that she could receive a breast cancer diagnosis.

4.2.3. Yes me.

As illustrated above, certain participants could not believe that it was happening to them. Conversely, two participants reported different responses to their diagnosis. One participant stated that she was not shocked when receiving her diagnosis due to its prevalence. While the other participant never wondered why she has breast cancer, instead she was thankful to God. In addition to these two participants, one participant gave contradictory responses regarding how she felt about her diagnosis.

At the stage when I found out I was not shocked really at all, you always hear of women with breast cancer so it was just (pause).. me now. So basically now I also have cancer. I didn't go into that mode of you know this is the last of me. So one of these days you are dead, because you hear a lot about people dying from cancer. (Amy)



The pause may indicate that it may have been difficult for Amy to reflect, she paused when noting that she now has breast cancer. Stating “so basically now I also have breast cancer” gives one the sense that it does not seem as a big deal to her. This is supported by the word “just” when stating “so it was just me now”.

I never thought of death, that was never a part of me. Sometimes we go why me, which I would never ask that. It was always thank you God for being with me through this journey. (Penelope)

Penelope never considered thoughts relating to death as a part of her, but rather adopted a thankful attitude towards God for being with her throughout her journey. She never wondered why her.

My mind was just to get better, so my mind was not on the negative. I was never sad too much. I never got to the point where I drowned myself and asked why why why and I just focused on getting myself better. (Sandy)

In the previous subordinate, Sandy notes that she wondered why she received a breast cancer diagnosis and not someone else. However on the other hand, in the extract provided above she notes that she never asked why but rather focused on the positive. In the previous subordinate Sandy uses the word you when stating that “you wonder why you”. This indicates that Sandy does not personalise her statement which may indicate that it is difficult to realise that she has breast cancer and that it is difficult to take ownership of those thoughts. While the acceptance of a breast cancer diagnosis may have been unexpected and characterised by shock, breast cancer treatment gives rise to emotions and difficulties relating to body image and identity. These results are presented in the section to follow.

4.2.4. Betrayal by the body.

Two participants felt healthy and therefore did not expect a breast cancer diagnosis. The feeling of betrayal by one’s body was evident in this study. This was the case for the two participants below:

Ya you don’t trust your body anymore, pause, I mean they told me I have cancer. I have no family here, I am alone. I felt 100 healthy and in my body there was a deadly disease growing and I felt strong and that was not the case. (Mary)

Mary indicated that she does not trust her body anymore because what she felt and what was actually going on inside her body were worlds apart. Due to the betrayal she felt, she in turn expressed her level of suspicion and worry when she felt ill.

I mean I struggled to get rid of my cough. Was so scared that I have lung cancer. I had it checked out and everything was okay. (Mary)

Another extract from a different participant relates to this theme. This is displayed below:

I live a balanced lifestyle, eat healthy, exercise regular. I must honestly say, I never ever felt like a sick person. (Gaby)

From the extract above we see that Gaby looks after her body through healthy eating and exercise which may have influenced the fact that she never felt like a sick person. This in turn displays the betrayal that she experienced because of her body being rendered ill. She never felt physically ill however she was diagnosed with breast cancer.

4.3. The effects of treatment

The experience of breast cancer treatment has been a difficult one for all participants. The loss of hair and breasts was found to be a threat to their femininity. Additionally, the physical change experienced by participants had an impact on others such as family members. The reaction from society has been reported as an aspect impacting the emotional experiences of participants. These results are presented in this superordinate theme through five subordinates.

4.3.1. Experiencing chemotherapy and the loss of hair.

The loss of hair was a major factor for most participants. Their response to chemotherapy and their feelings regarding the loss of hair is presented in this subordinate theme.

When I was told I will have to undergo chemo, I was scared for the moment, thinking about my hair that will fall out. I had a mastectomy one breast only and had preventative chemo therapy for 6 months afterwards. Emotionally, I was fully prepared for it. I was worried about my hair, but quickly made peace with it. I lost my hair 17 days after my 1st session of chemo, but was well prepared. Had my wig sorted and had it ready for when I needed it. (Gaby)

The first thing Gaby thought of after being told that she will undergo chemotherapy was the loss of her hair. She mentions she had a mastectomy but focuses on the loss of hair. This could be because it is easier to cover up the loss of a breast or it may be less obvious. Gaby goes further by reflecting on her chemotherapy experience and the effects she experienced after treatment.

As I sat one day before chemo started, a tear fell down my cheek, and I knew it is only vanity making me sad, I must be grateful for the healing process to follow. And that was that. (Gaby)

Gaby reflects on her emotions experienced when chemotherapy started and the reasons behind it. She knew that she felt sad about the physical impact treatment will have on her body. She states however that she “must” be grateful indicating no choice. That is how she “must” feel.

I didn't sit and think oh my hair. I didn't feel shy when I cut my hair because I'm used to wearing a cap and being relaxed in track pants so it was fine my hair grew quick, I cut it immediately when it started falling out. (Amy)

I am someone that is very easy so I can deal with anything. I can cope. My hair fell out a lot and I got very sick so I thought no I'm not doing chemo even if I must die then I must. (Amy)

Amy, in her experience of hair loss notes that she was not concerned about it. She reflects on the way in which she presents herself and that due to this, it allowed her to not feel shy regarding her hair loss. Another point influencing her reaction to the situation is the fact that she notes that her hair grew quick which leaves less time to notice how short her hair may be. Conversely, in the second extract above, Amy states that she can deal with anything however she also states two important points influencing her thought of death instead of chemotherapy. These two points were the loss of hair and the side effects she experienced. These two factors were so difficult for Amy to deal with that she instead preferred dying to chemotherapy. Additionally, Sandy reflects on the way the loss of hair affected her:

I must say with your hair falling out it does affect you a lot and I cried but eventually it was so bad that I just shaved it off and put on the wig then you just look down. It's difficult to see myself with short hair but at least I'm telling myself it's my own hair, my head is not so cold in winter, don't need to put a scarf over the wig. With the wind I must hold my hair. It takes away from you, coz you felt younger but now you feel older. (Sandy)

The loss of hair affected Sandy immensely. When it got “bad” she used a wig to cover up the loss of hair. She notes that she just looks down which may indicate embarrassment, feeling ashamed and judged. She identifies that it’s difficult to see herself with short hair but that it’s not as bad because it’s her own hair. However, even though she notes it’s her own hair which may allow one to think that she is not making use of a wig, she notes that in winter she doesn’t need to put a scarf over the wig. This thus means that she does make use of a wig. She goes further and states that with the wind she needs to hold her hair down which takes away from her youth. On the other hand, one participant reflected on new ways of making herself feel pretty. She also reflected on the time and money that she doesn’t have to spend. This is reflected below:

I was never going to become dependent on a wig so I had made a effort to say I will be a bold woman, I will start styling the scarfs and wearing the big ear rings which I did anyway. I want to be able to show people out there that you don’t need a wig to be pretty and funny enough I don’t feel different without my hair but I realise that when I walk into places, people look at me, but it doesn’t bother me, most of the time I forget I don’t have hair and it doesn’t bother me. (Ruth)

Ruth above states *funny enough I don’t feel different without my hair* which indicates an element of surprise in that she was expecting to feel different without her hair. She further asserts that she realises that people look at her differently when she walks into places which may at that point remind her of her illness and may make her feel different. She states that “most” of the time *I forget I don’t have hair and it doesn’t bother me*. Indicating that there are times when she does remember that she has hair and when this bothers her which may be when people stare at her.

I mean it’s actually great to not have hair, I save time and money on products (laughter) I don’t have hair on my legs so I don’t have to shave my legs so I save a lot of money on beauty stuff, but the strange thing is that, I look at photos I think that I will have hair again so when I’m walking I don’t think about my hair, I forget that I really don’t have hair but when I stand in a queue and they will like look at me or they will give me a look and I know that they probably wondering if I have cancer or not and then I have had people who have come up to me and said um... you actually carry your hair very well, It looks good on you I wish it

looked good on me, you know, cancer patients. They would also come up to me and say oh my word how did you do your scarf because sometimes I wear scarfs on my head turban style, or they would ask where did you buy your hat, sometimes I wear hats also so that I don't get freezing cold. The only thing about not having hair is that you constantly cold. (Ruth)

Ruth seems surprised that she finds it great to not have hair. This is illustrated with the word “actually”. She is pleased with the fact that she saves more money due to the lack of hair on her body. She thus brings to light the positive experiences she took from her breast cancer journey. Additionally, she highlights how she experiences the cold due to the loss of hair and the accessories she uses to help in this regard. Reminding herself that she will have hair again seems to help the way in which she deals with the loss of hair. She also reports the comments she received from other cancer patient. From their comments, one can see that there is an expectation that the physical appearances of cancer patients is unmanageable. That other cancer patients, when experiencing physical changes do not think that it looks wonderful on them, an important point which has self-esteem implications. When asked what she sees when she looks into the mirror, Ruth responded with the following:

pause... that's a tough question... when I look in the mirror I don't see me, I don't see the person I have known all my life because there has always been this bush of hair surrounding my face but what I do see is more of me so I don't see the person I used to be I see more of me. I see my big eyes, I see my blemishes is not as noticeable as before, um..i see my scalp, I see the tan line of my hair um, I just see difference and more of me with no hair and that's what people would say wow you know I didn't realise our eyes looks like that or nose looked like that or your ears looked like that because I had this huge bush of hair so.. and then I will look at a bland face and like aargh this is my morning face ok time to put on some make up and blush and lip stick and look good, look pretty and feel pretty so I do what I need to to make myself look pretty. Um.. ya so that's what I do. It's not a sorry for me face or something like that it's just ya, appreciating a different look. (Ruth).

As much as I am enjoying this openness, I am looking forward to having my hair back but I am looking forward to the different styles that I am going to experience along the way to get it long again. (Ruth).

Ruth mentioned that answering what she sees when she looks in the mirror is a hard question. This may be due to the physical changes she experienced due to breast cancer and having to reflect on this may be difficult. She states that she is not who she was because her physical appearance changed somewhat. Her experience of breast cancer has allowed her to see more of herself. She as well as others are seeing herself more clearly due to the loss of her hair. To feel pretty when she feels “bland” Ruth uses make up which works for her. She tries to make the most of her new look. Below Penelope provided insight to her experience of chemotherapy and the loss of her hair:

I also cried when they told me I was going to get chemo. It's not like I didn't know, I knew but then it was a reality. So it was like, a surprise but I knew I was gonna get it. It was like hitting me all the time like it's happening. I think it's because I knew that I was going to lose my hair. Because I cried when I lost my hair because I had to cut it. It meant like, this is like really happening, that there is evidence now. (Penelope).

Penelope displays how difficult it was to accept that she will be receiving chemotherapy and that she will lose her hair. She knew that it is something she will have to go through but still it was surprising for her and this may be due to the fact that now it is becoming a reality. There is evidence showing that one has an illness. On the other hand, she experienced other emotions which are provided in the extract below:

Also I was excited to go for my first chemo, I was like finally I'm starting to fight this. I was so ready for the challenge... I was excited, I was excited, I kept on counting down how many I have left. (Penelope).

While it was difficult to come to terms with the fact that she will receive chemotherapy and lose her hair. Penelope reported that she was excited to start chemotherapy. This was because it will symbolise the start of her fight against breast cancer. She provides insight into the level of excitement she experienced but stating that she counted the number of days she had left till her chemotherapy sessions. Above, Penelope states that she cried when she heard

she was going to receive chemotherapy due to the loss of hair she was going to experience. Another extract sheds light on her feelings after having lost her hair.

People at work would tell me oh you look so nice with your hair like that. Mxm they lying man, they all lying to me. Laughing! They were just saying that. (Penelope).

Penelope did not believe it when her colleagues would inform her that she looked nice with her hair shorter. This indicates that she believed that she did not look good, highlighting her insecurities and self-esteem. When speaking about her occupation, she stated that she works in theatre and reflected on how it feels having breast cancer while working in a hospital.

I really didn't like being a patient. I didn't want to be treated as a patient, i didn't feel like being a patient at all. I really didn't like going for examinations where they touching you. I use to hate it. Sometimes you just lay there and then there are four of them just busy. They touching you, positioning you you know, you feel like they the bad guys. (Penelope)

Penelope did not like being a patient. She had to be on the other side of the medical bed which appeared to be difficult for her. She indicates a loss of control over her body stating that she just lays there while being touched and positioned. She therefore felt as though “they” were the bad guys, referring to the medical professionals.

4.3.2. Womanhood, breasts and scars.

Breasts have been identified as an important aspect to being a woman. A few participants in this study found the thought of a mastectomy difficult while others struggled with the insecurities of a mastectomy. These results are presented in this subordinate.

I never had a mastectomy, a lot of people are going for that and I think that because you already going through so much with the cancer, so you taking away your womanhood, you taking away your life so why remove that? (Sandy)

Sandy identifies the prevalence of mastectomies but states that experiencing cancer without the loss of breasts is hard enough. She views a mastectomy as something that takes away ones womanhood and life. Breasts for her therefore represent ones womanhood

Also the physical aspects of this experience affected me and my husband. He would squeeze me and would be afraid to touch my boobs. I mean I don't see the scars and at least I still have my boobs. (Sandy).

Additionally, Sandy reflects on the impact her physical aspects of her breast cancer experience has had on her husband. The physical effects of breast cancer affected the way in which her husband was affectionate with her. She states that “at least” she still has her breasts indicating that for her losing ones breasts is worse than having scars. Another participant reflects on the point made that womanhood involves having breasts:

Everyone asked me why don't I have a mastectomy, I always responded okay, it's easy for you to tell me that but I'm a woman and I'm used to having two breasts so really it didn't sink in that I'm sick because I'm positive...but now what will happen to me if I removed both breasts?? How will it affect me then? I wouldn't handle it, coz now I can handle it because I see it. (Amy)

Amy states that for others it's easy for them to tell her to have a mastectomy and this may be because they are not the ones diagnosed with the illness. As a woman, Amy states that she is used to having two breasts but also makes reference to being positive as a reason why it did not sink in that she is sick. However because this is stated immediately after stating that she is used to having two breasts, not having two breasts may act as a reminder that she is sick or as a factor displaying her reality. She also goes further and states that she would not handle losing her breasts. It is easier to deal with her illness now because she can see her breasts and know that it is there which supports my point made earlier. Another participant expressed her uncertainty regarding the removal of her breasts following her diagnosis.

When I got diagnosed I didn't know if they will remove it or not. I was shocked but then I thought it's not important. I want to live. I was happy that everything is still here. I mean they only removed the lump, they didn't take the breast. It's only a scar. (Mary)

Mary states that she was shocked about the possibility of her breasts being removed but for her living was more important. She also viewed her scars as not as bad as having ones breast removed. Furthermore, when being asked about emotions during the treatment process, Mary responded with the following:

It was actually fine. The only thing is that there are a lot of old people in the waiting room. I felt very misplaced. I just felt out of place. I mean it's never nice to get it, but rather at a older age where you have lived your life but no one wants to have it of cause. (Mary)

Mary felt very misplaced in the waiting room due to her age. She notes that there are a lot of older people in the waiting room. She expressed that one should rather receive a breast cancer diagnosis when one is a bit older because at a younger age, one has not experienced life yet. She identifies that it's never pleasant to be diagnosed with breast cancer but it may be a bit better in a sense at an older age.

I had no breast, I always made fun of it actually, the thought of not having a breast. I joined the gym and I spoke to this guy. He told me imagine someone who lost a limb that you can see... you, you just lost a breast that you can't see, you can cover it up so it didn't affect me that much. Obviously there are some insecurities now and then when you wish you can buy certain things but you can't buy it because of my breasts. (Penelope)

Penelope found the thought of having one breast amusing and notes that she always makes fun of it. This may be her way of coping with the situation, to express her emotion through humour. She also makes reference to a lived experience. She mentions that she spoke to someone at gym who informed her that she just lost a breast and compared her loss of breast to the loss of limbs that's visible. What he said to her reduces the impact of losing a breast. She states that it didn't affect her that much indicating that it did affect her. She also makes reference to her insecurities she experiences when she is limited by the clothes she can wear. She makes further reference to clothing and the stares she would receive from people that in turn allowed her to reflect on the option of reconstruction surgery:

When I wear certain clothes and people look then I feel like they looking right through me and that they know. I recently discussed reconstruction. I was considering it but now I think I should just leave it for now. It doesn't matter for now. (Penelope)

Penelope reflects on how she feels when people stare at her. This is influenced by certain clothing she wears which relates to the point made earlier that she feels insecure when she cannot buy certain clothes. She informs us that she feels exposed and transparent, as if people can look through her. She mentions a point relative to her feeling insecure and transparent which is the option of reconstructive surgery. She was considering this option possibly due to the feelings she experienced however she states that it doesn't matter for now indicating that it might matter to her at a later stage. Ruth had a scheduled mastectomy which is what she refers to in the extract below. She provides insight into how she is feeling about the operation and the concerns she has

What I am.. I think a little bit (pause) worried? (pause) wouldn't be the right word, um concerned? I don't know (pause) is when I have my mastectomy. So what I'm concerned about is maybe the scars and how will the scars look, will it be painful I hate pain. (Ruth).

Ruth was unsure of how she felt regarding her scheduled operation. It appears as though it may have been the first time she thought about how she feels about it. She then states she is concerned about the scars and how this may look as well as the physical pain she might experience. She first mentioned a concern regarding the appearance of the scars and then the pain which may indicate that the physical effects of the operation may be more of a concern for her than the physical pain she might experience. Similarly, Penelope wondered what others might think about her only having one breast:

Well I can't have children anytime soon, and I wonder about meeting a guy you see, and how he would feel with you just having one breast. Also with family, you know especially with girls your mother will come in while you getting dressed and so on, now you just want to hide it, how is she looking at you, what are they thinking when they see the scars and one breasts. (Penelope).

From the extract above, Penelope states that she cannot have children anytime soon highlighting that breast cancer has implications for fertility. Additionally, Penelope indicates that having one breast is something out of the ordinary and may be something that affects the way in which a future partner may feel about her. She was very concerned with what people may be thinking of her reflecting her insecurities. Even when it came to family, such as her mother, Penelope wondered what she may be thinking about her body.

I mean I'm laying there with just one breast and I think what are these people thinking of me. I wanted that to finish so that they could stop staring at me. I mean they look at my age and they could say this person is young and they going through this. (Penelope).

In addition to her concern regarding what a future partner and family members might think about her breast, Penelope was concerned about what the medical professionals might be thinking about her due to her one breast as well as her age. In addition to her physical changes that affect her self-esteem, being diagnosed with breast cancer at her age influenced how she felt about herself.

4.3.3. Effects of physical change on others.

The physical effects experienced by participants appeared to have an effect on others such as their family members and friends.

I prepared him for the chemo, for losing my hair because that was basically the only visible thing that he would have to face. He said balled heads freaked him. (Gaby)

I wanted a smooth process and wearing a wig made it easier. I did not want my son to be reminded of the chemo and the cancer and walking around with a bald head is a constant in your face reminder. (Gaby)

Gaby speaks about her son and states that she had to prepare him before receiving her chemotherapy because he was uncomfortable with bald heads. She adds to this by noting that a wig made the process easier for her son. She did not want a constant reminder of her illness

for his sake and would therefore use the wig to cover up what was happening. Similarly, Sandy's brother did not like her bald head, this is illustrated below:

My brother would not talk to me directly and look at me, he didn't like the bald head. He would use something so that he doesn't see me directly. I said to him don't do that because you give me the impression that I'm sick and I don't want to be treated that way. I want to be normal and be accepted in society. Don't treat me like a cast out. You basically feel that way. Don't look, other people will carry on, I put on more weight and I said to them it's the treatment but don't look at it. Just let me do what I must and get over it. It was probably difficult for other people as well to look over how I look. People can play a big role. Sometimes you okay and you fine but they make you feel different.. Sometimes the family and environment can make you feel like you not the same like you are put into a box.
(Sandy)

Due to her brother's dislike of her bald head, he treats her differently which she interprets as treating her as a sick individual. She states her desire to be "normal" and accepted in society sheds light on the way that she feels which is abnormal due to her physical appearance and not being accepted into society because of this. She mentions how she explains to people that her weight gain is due to the treatment and that they should not look indicating a level of shame or embarrassment. The way she felt about her physical appearance is evident in the statement she makes about it being difficult for others to not take note of how she looks. This seems to reflect a low self-esteem. At times when she feels "okay" she states that people would then make her feel different. This may come from the way in which people treat or look at her due to the physical changes. Ruth, reflects on her daughter's behaviour who reported that her mother was not well which ultimately affected her emotionally.

My daughter had an outburst at school and I mean she is only three where she was so sad and when they teacher confronted her she just cried and cried and said my mommy has a eina on her boobie (quiet, seems thoughtful, sad) I think that what she referred to was when they did the biopsy they clampt my breast so they left bruising so they could see the bruising and could relate that mommy had a eina on her boobie. (Ruth)

Ruth's daughter was affected by the breast cancer process because she saw the bruising which indicated to her that her mother's breast was sore. On the other hand, Ruth also mentioned that her children were supportive and tried to reassure her.

My kids has been so great you know, they often come to me and touch my head and say mommy you know we love you like this we love your hair, that meaning the fact that I have no hair, they will touch my head and say mommy you look beautiful, so it's amazing how they for some reason want to reassure me that it is okay. (Ruth)

The different response to the breast and bald hair may be because a bruise was visible on the breast indicating pain whereas with a bald head, it may be seen as a different look but is not associated with pain. Furthermore, Ruth mentions an event where the effects of breast cancer treatment affected the way in which children interacted with her and why she believes that is the case:

I was at an event last week where all the ladies there had wigs and what was strange is that they all said to me oh we all have wigs because we don't want the kids to see us without hair and I had a few instances where kids have kind of shy away from me because I don't have hair, like when I take my kids to a kiddies party, kids that will normally come up to me and hug me hello will now shy away because of the fact that I don't have hair at the moment. (Ruth)

My personal opinion is that maybe society has made it known that it's not okay to walk around with no hair so even for these little girls I mean when you think of the little cancer girls, kiddies in hospital they don't have hair either and they shouldn't be made to feel like outsiders you know. (Ruth)

Due to the fact that Ruth chose not to wear a wig, children interacted differently with her. Ruth believes that society has shaped the way people think about the loss of hair and that they should not be made to feel like outsiders. This may reflect the way Ruth feels when people shy away from her due to the loss of hair. Similarly, the evidence of the illness affected Amy's son:

My son was very upset, when I went to cut my hair off. So I had to explain why I had to do it. He had a problem at the school, a family member's child at the school then told the teacher what's going on. (Amy)

Amy's son was upset when she cut her hair. This may be because it is a visible sign that she has breast cancer.

4.3.4. Side Effects.

As noted earlier, the loss of hair had a major impact on the emotions of participants. Besides experiencing this side effect from breast cancer treatment, the majority of participants did not experience any severe side effects.

The side effects I experienced, I was tired and nauseous but other than that I was fine. Sometimes it's all in the mind you know and what you tell yourself. (Penelope)

I didn't lose the weight through chemo I gained weight. People will always say are you sure that you have breast cancer because I gained instead of lose weight. People kept asking am I really sure. (Penelope)

Penelope did not experience any severe side effects. She also viewed ones mind-set as a factor which may influence ones side effects. She also states that instead of losing weight through treatment, she gained weight and because of this, people question her diagnosis. She brings to light the fact that losing weight has been associated with a cancer diagnosis. Similarly, Gaby never suffered any severe side effects, instead she found that she had more energy and was therefore grateful for this. This is indicated below:

During Chemo, I was 100% fine, thanks to GOD ...I never suffered any bad side effects. My hair fell out, my nails stained, and that was it. No nausea, no nothing! After my Chemo session, I had so much energy, I could hardly sleep at night. The next day I was in gym for the rest of the week. I was extremely blessed during my treatment. (Gaby).

More participants reflected on their experience of side effects:

I have not have any side effects. (Mary).

I had nausea and I just used vinegar to settle my stomach when I feel sick. I must say it was a smooth process. (Sandy)

Mary reported having no side effects. In addition to Penelope and Gaby, Sandy reported that her treatment process was smooth. This may be due to the minor side effects she experienced. She also states her way of dealing with her nausea when she felt sick.

I try to make light of my situation, it doesn't just have to be doom and gloom um.. and once again maybe I am not feeling it, because my friends are like aagh it's been terrible I know you had a bad one you know but then I just sleep it out, I come home and try and get a few days of rest and I pray and I sleep and I pray and I sleep and then I'm fine again and ready to move forward. Even now I got cramps in my leg, it's a new side effect from the treatment, its pain in my bones. (Ruth)

The first one was an absolute breeze, it's also the one that makes your hair fall out. I thought that if I could do this then I could make it through all four but then the last one was probably the worse and I was the most sick. (Ruth)

Ruth in her reflections above tries to make light of her situation meaning she may talk or behave in a way that treats her situation as unimportant or humorous. An important point to note is that she made light of her situation whereas her friends would remind her of the terrible situation. To deal with this, Ruth focused on resting and on her spirituality. In the second extract she refers to her chemotherapy sessions where the first one went well which made her think that she could make it through the rest, however her body responded differently to the last session which made her the “most” sick. The use of “most” indicates that she did get sick with the other sessions but not as sick as she did with the last session of chemotherapy. Similarly, Amy states the effects she experienced when going through chemotherapy.

My hair fell out a lot and I got very sick. (Amy)

Amy mentions that she got very sick. One can see from the experiences of all participants that some are similar while some are different. Participants shed light on their emotional experiences throughout their breast cancer journey thus far. For some, a breast cancer experience has been characterised by silent suffering.

4.4. Silent Suffering

Silent suffering is a super-ordinate theme with two subordinate themes namely; *A lonely journey* and *Cannot be understood*. The silent suffering experienced by participants flows throughout these subordinate themes.

4.4.1. A lonely journey.

This subordinate theme shed light on a journey that has been described as “lonely” by a participant. Although the other participants did not use that specific word, the reflections below shows that the experience of breast cancer has been one of silent suffering.

Um, you get to a point where you feel lonely, you feel like you can't speak to anyone else just the lord. And um you (pause) feel ashamed of yourself, why did this happen to you, did you do something wrong, um that kind of thing, but you basically feel lonely. It's like asking all these questions and no one is answering you because no one can give you the right answer. It's like a road all alone, all quiet, it's just the wind, eventually you must hear what the lord must tell you. (Sandy).

Sandy felt lonely through her experience and felt as though she could speak to no one. No one could give her answers to the questions she had. In addition to sharing how lonely this experience feels for her, Sandy reflects on this further by giving more detail and adding another graphic representation of her emotions.

Even your husband can't help you. Because when they get emotional, you get emotional then everyone is emotional so you must be strong. I never had time to cry at home in front of my husband and children. There was never time to say ok I want to cry today. Sometimes I would look at myself and laugh and cry and laugh and cry. But it's like me and a mirror but there is no one to help you

through this that's why you must put this shield around you and carry on with life. Also you can't speak to everyone about this. (Sandy)

Sandy recounts how she had to be strong for others. If she shows emotion then this will affect her family members. She therefore states that she “must” be strong. She also mentions time in that she never had time to express her emotions in front of her family. This may reflect how busy she is as a wife, mother and during treatment. However, she went further and states that sometimes she looks at herself and laughs and cries indicating that she had time, that it may be easier to express herself when she is alone. Her response also reflects confusion regarding how she feels. She laughs and cries. When asked why she can't speak to anyone, she responded with the following;

You speak but not that inner inner that is bothering you. I also heard my husband was emotional at work but he would never be with me or in front of me. Also doctors I found don't really speak openly about cancer, it's like it's a swear word. My doctor called it CA, I think because they thought they make the people feel comfortable but it's like they whisper it. Even other people, they don't want to speak about it. (Sandy)

Sandy mentions that one can speak to people but that you do not reveal everything that is bothering you. Sandy's husband got emotional at work instead of with Sandy. This may be because he does not want to trouble her with his emotions. Sandy also reflects on the way breast cancer is dealt with in the medical world and in general. According to Sandy, people do not speak about breast cancer. It is so taboo that she associates it with a swear word. Similar to Sandy, Penelope protects her family from distress. Penelope reflects on her silent suffering below:

I think it's because I am alone here. I didn't want to worry my parents because if I cry then they worry like what must we do, must I come down. My mom asked must I come and I said no I will come when I'm better. I would tell them I'm fine because I don't want to worry them, I don't want them to hear me crying I don't want them to know how much it is hurting me. I didn't want to put a lot of stress on them and have them having high blood pressure because you are sick. (Penelope).

Penelope did not want her family to worry about her and would therefore not express how she was honestly feeling. She states that she didn't want her illness to affect their health. She however uses the word "you" instead of "I" implying that it may be difficult for her to say that she is sick.

4.4.2. Cannot be understood.

Thus far we have seen that participants kept their emotions to themselves in order to protect family members. Additionally, not expressing emotions came from the idea that people will not understand their breast cancer experiences.

I think that other people, people from outside can't understand, I see it at work you know (pause)... you have to have been through it yourself to understand fully the extent. You have to go through it yourself to understand what it's like. (Mary).

Mary believed that the only way one could understand what experiencing breast cancer is to be diagnosed with the illness. Penelope however, did not access any counselling because she believed that no one will understand her experience and tell her what she would like to hear due to the uncertain nature of her illness.

I didn't go for counselling, felt like they would not understand and they would not be able to let me know what I wanted to hear which was I was going to be okay. Because they don't know. (Penelope).

My one cousin came to see me, she thought I was dying on my death bed. When she saw my scars she would ask how do you feel, I would say I'm fine. I mean you don't want people asking how u are because they won't understand. (Penelope).

This last extract above speaks to the silent suffering theme as well as to the subordinate theme cannot be understood. She would not inform her cousin how she was feeling because she believed people would not understand. Due to the fact that she would not express her emotions, it was thus a silent journey.

4.5. Coping Strategies

When asking the participants what they would want others to know about their experience, the way in which they coped was evident in their responses. However with certain participants their means of coping came through during the interview at various points. Spirituality played a major role in their lives as well as positive thinking. This is therefore the first subordinate theme. Within this subordinate theme, the meaning that certain participants gained from their experience was on a spiritual level. Another way of coping identified, was related to their support network and this is reflected in the second subordinate theme namely; reliance on the self and others. Lastly, certain participants found that educating others about breast cancer, assisting them in coping through their journey. This is the last subordinate theme namely; educating others as a way of coping.

4.5.1. Spirituality, positivity and finding meaning.

Spirituality was a major source of support, comfort and meaning for participants. Additionally, being positive was regarded as vital through difficult times.

I think most of all you know just having my faith close to me and really just praying about it and making the right decisions and then I think doors just started opening and information just starting coming in to help me make the right decisions. (Ruth).

The above extract illustrates how important spirituality was for this participant. It also sheds light on the meaning she makes from her experience. She continues, at two different points during the interview, highlighting that God and a positive attitude helped her cope through her journey which is presented below.

There was just real honest clarity and faith in god that has a plan. He knows what I am supposed to learn out of this um...he doesn't do bad things to us, we just have to believe that he will help to heal us. So this has happened to me, so I guess I have to look around and see what the lessons are and take what I can out of it and that's what I think the approach I have taken from day one. (Ruth).

um...long pause, I think the emotional experience is (pause....) for me it has just been to have God on your side, that's really I mean it's the only thing and I unfortunately know that there are a lot of non-believers out there but if you can

just believe in anything and have some sort of faith or have something that you can believe in whether its supernatural powers or God or Allah or whoever you want to believe in, just to have some form of faith because that is what will make you stronger through the journey, that's what going to keep you focused and positive throughout this journey because that is the only thing that you can rely on 100% so also it's not a matter of oh when you feeling sick or not feeling good like oh God was not there for me he didn't provide for me that's not what it's about, it's about knowing this is your journey, this is a journey that you have to follow. (Ruth).

Ruth believed that God has a plan and that there is a reason why she is going through this experience. She believed that she needed to learn and understand what the message is that she is supposed to gain from her experiences. Her strength came from her spirituality and belief in God. Being content with her journey gave her a certain level of peace and strength.

Even though I say I have no anger and hatred, there are moments of weakness where I ask why am I going through this right now, why couldn't I take my kids on this wonderful holiday but then I quickly snap out of it and say that there are reasons, you will understand it when the time is right. You got to be strong. Allow yourself this moment of sadness but then also think positive and move forward. (Ruth)

Ruth refers to “moments of weakness” when she experiences anger, hatred and questions why she is going through what she is at that present moment. She counteracts these feelings by reminding herself that there are reasons for what she is going through. Timing thus comes through as an issue but also as a comforter. In her response above, being strong was imperative, you are allowed a moment of weakness however one needs to be positive and move on. She also speaks to the theme presented above where participants wondered why me, however the essence of this extract reflects the emotions experienced and the emphasis placed on having to be strong. Similarly, Amy reflects of being positive:

All that I can say is that you must stay positive I will say it's better to be positive regardless of anything and everything. Regardless of what the doctors say because god drives our lives. If it's your time it's your time. Just because you

have cancer doesn't mean you will die. What you believe is what will be. So if u believe you healthy that's it. So I can't sit and be negative, I was never negative so regardless of your situation, it costs nothing to just go on your knees and ask god for wisdom and health. (Amy)

Above Amy reflects on positivity, the power of believing as well as her faith. Notably she states that one “must” stay positive. She went further and reflects on the meaning she took from her experiences.

To be honest I am not one that will sit and mope or think about cross questioning God because things that happen is what is supposed to happen to you. So everything that happens, the tests and stuff along the way is part of my way forward. (Amy)

Amy believed that the experiences that she goes through are what she is supposed to go through, that this is her journey. She identifies herself as someone who remains positive and who does not question the things that she goes through.

My gratitude and positive attitude, I believe carried me through this ordeal. Physically, there is scaring, a whole new breast, looking different from the other one, but I am only grateful that I am a victor and not a victim. (Gaby)

Gaby identifies her physical changes however she views herself as a victor. Her gratitude and positivity played a vital role through her experience. She believed that these aspects helped her through her experience of breast cancer. She provides advice to others battling with breast cancer:

Be positive, for a positive mind already overcomes 70% of the illness you are diagnosed with. Your mind is powerful, so let it be. (Gaby)

Adopting a positive attitude or mind-set is recognised as a factor influencing one's health. Gaby believed that it was all about mind over matter. She gained this perspective from her lived experience. In the extract above, she notes that her mind-set carried her through the tough times which gave her leverage to provide the advice given for others. While certain

participants such as Ruth and Sandy who searched for meaning from their experience of breast cancer, Penelope did not wonder or question her experiences but rather asked for strength from God to get through the difficult times.

Instead of blaming and trying to find out where it came from, it's there so I just tried to get the strength and carry on with it. I'm Christian and that has helped me through the journey. I would always pray before a test. (Penelope).

Penelope found it strange that she became emotional when dealing with a patient who had a mastectomy. She reflects on how she found it difficult to tell others to be positive when she was going through a difficult time.

What's weird is that in theatre we had a mastectomy patient and I got emotional at one point, it was like difficult to see others and sometimes it was difficult for me to tell a patient it's going to work out when I don't know, I'm not too sure now after going through what I am. (Penelope).

Additionally, due to her experience of breast cancer, Penelope found it difficult to be positive and inform others that their outcome will be positive. Similarly, Sandy reflects on a difficult time for her, which is presented below:

I was actually upset and you get upset with god too, you think he doesn't love you anymore, why is he putting you through this. But then you focus on being healthy and just um appreciate life and trust in him and doing the right thing. (Sandy)

Sandy was surprised that she was upset in general and with God for putting her in the position she finds herself in. However, Sandy then felt different and started trusting that God has a plan.

4.5.2. Reliance on the self and others.

Most of the participants identified their support network as family, friends and work colleagues while others preferred relying on themselves. The two participants below received

support however, they either preferred relying on themselves or believed that they did not need support.

Then I found out it was cancer, my boy lived with me that time still, I told no one, no one, no one in my family. I kept everything to myself. You see (pause) I am someone that is very independent so my business is mine not for everyone else. So whatever must be sorted out I do it without family. So even if I don't have food, I won't tell anyone I will figure it out myself. I got a lot of support but I'm better on my own because my family was never there for me throughout the years. (Amy).

Amy reflects on the time she received her diagnosis and notes that it is in her nature to not confide in anyone and to be fully dependent on herself. She is aware of the support she received, however due to past experiences where her family was not therefore her, she believes that she is better on her own.

My family did a lot but they also charged me with petrol (laughs). The support of people working with you is also good because they are there. I never needed support you know. I was never sick of being sick (laugh). For me it was getting it over and done and then life goes on. (Sandy)

Sandy notes that her family assisted her but that they received something in return. She recognised that it is good to have support around you but that she did not need it. Her focus was getting through her experiences and moving on.

People are very rude, they stare and it's terrible but they not fighting your fight and if you are glad you there for your family so why must you be bothered by other people. You going to work to survive so you must not be bothered. You must put up this shield and go on with your life. It's difficult but just put up the shield. (Sandy)

In the above extract, Sandy speaks about a “shield” which she uses as a coping mechanism in order to protect herself from the people which she experienced as “rude”. More participants reflected on their support network.

Lucky for me I have a very supportive husband and family and friends so I have been very blessed. This is a family issue and everyone needs to be involved.
(Ruth)

I have no family here, I am alone but I have a lot of friends supporting me.
(Mary)

Ruth considers it a blessing to have supportive family and friends. On the other hand, Mary notes that she is alone however she has friends providing support. The participant below reflects on a loved one leaving due to her diagnosis and how she wanted his support through her experience. She also reflected on the support from her colleagues and support group. Lastly, she goes further and highlights how she relied on herself through her experience.

My department has been amazing through everything and also a support group I am a part of. For me that has been a part of my healing process. (Penelope).

I have a scrapbook and I wrote a letter to myself (pause), dear me, if I was your friend I would be so inspired, you don't know how much you inspire me and encourage me to go the extra mile. I don't wanna be teary, (laughter) (reassure her it's okay to feel that way), God was walking with me, the person who was my right hand was me and god, in the chemo room. I didn't have anyone, it was me myself and I (pause), that's why I wrote the letter. (Penelope).

Even though she identified that her colleagues and support group has been a major part of her healing process through their support, Penelope still notes that she didn't have anyone, that she had herself. She admired herself and knew that God and her own strength helped her through her journey. Additionally, she mentions how she yearned for the support of a loved one:

I had a partner he was there at first and said he will stick through everything but the heart breaking thing is never once was he there when I went for chemo or any other test. He told me once that he was scared. I guess it was a shock for him but as time went by the love we once had left with the cancer, just like him. I never really had someone to hold my hand and say it's going to work out even though I knew it will be fine it would have been nice to have your partner next to you. I

honestly wanted him to be there just once but it never happened so that disappointed me because in the hardest time's you want the closest to you the most. (Penelope).

Penelope reflects on the heartbreak she experienced when her partner left her. She also reflects on her desire for loved ones close to her during hardships, in this case, breast cancer.

4.5.3. Educating others as a form of coping.

In addition to spirituality and positivity, some participants found that educating others about breast cancer and sharing their experiences made them feel good about themselves.

Definitely what helps me also is social media, speaking about treatment and how I'm feeling, posting inspirational things as well as prayers and educating people about what cancer is really about and the effects of cancer and also be a motivator for people to go for their mammograms. I mean I waited, I felt a lump, I knew it was there I just never thought it would be cancerous. I mean if you catch it early you know it's better to not go through such stringent treatment. (Ruth)

Ruth states that she educates people about what cancer is “really” about. Indicating that people may have certain expectations but that it is different to those expectations. Educating others regarding the importance of mammograms was vital for her because of her personal experience with breast cancer. Another participant reflects on how it’s possible for her to assist others:

I mean it's become like flu now, it's an epidemic. There's lots of people who does not understand everything and they immediately think it's a death sentence and I would tell them, at least they found it, get yourself better, just get it out of your system, follow the doctors and move on. I can at least give advice now. I mean there is help. Even with TB and HIV, people think they going to die but they live so long. There are things you can do. I think why people have a negative view about cancer is that they detect it too late and they can't cut it out. That's why people by 25 must be cautious and get their check-ups. I mean I screen

papsmeers but I don't go for ones. Now a days you must be more alert and go for check-ups but go for mamos. (Sandy)

Sandy reflects on a point made earlier by Amy relating to the prevalence of breast cancer but goes further and states that there is a lack of understanding of breast cancer and what it entails. Notably she states that “at least I can give advice now” indicating a sense of purpose that she may not have had prior to her breast cancer diagnosis.

4.6. A Turning Point

Through their experiences, participants gained new perspectives on their lives. They experienced a turning point which, for some, gave meaning to their experience. This turning point involved certain participants adopting a new lifestyle, focusing on themselves as well as appreciating others and life in general. Below are extracts from participants experiencing these turning points.

Like through this whole experience I learned that I should put myself first, I don't neglect my family, I sort them out but I know I'm an option and I'm taking care of myself. I also try to sleep more now and just relax you know. So I make special time for that and for five fruit and veg a day and to exercise and to put the stress levels low and at least up to a litre of water a day because I never used to drink water. At least I'm doing something.....I had to relax from work also because people will add on you stress and they don't know you getting tired of them being difficult...I must look after myself and eat right, sleep, exercise, spend time with family. (Sandy)

Sandy reflects on what she had learned through her experience thus far. For her, putting herself first was important, however, she notes that she does not neglect her family. Making sure it is not assumed that through her taking care of herself, as a mother and wife she doesn't neglect her family. She also states that within a difficult situation she is doing something, and for her this is at the minimum. This is illustrated with the words “at least”. She notes how she makes time for a healthier lifestyle because she did not in the past. Furthermore, Sandy mentions the same point at a different point during the interview.

Eventually it becomes spiritual and what do you get out of this? What is the message? I must look after myself and eat right, sleep, exercise, spend time with family and realise life is precious and don't take it for granted. So appreciate things more. (Sandy)

Sandy notes that eventually, through everything that she went through, she wonders what the message might be for her through her experience, she searched for meaning. For Sandy the message she gained through her breast cancer experience was about looking after herself, spending more time with her family and to appreciate things in life. A similar point was made by Amy, this is illustrated below:

I mean you give and give and give for other people but never for yourself. I never had time for myself basically and now was my time. (Amy)

Amy starts by reflecting in third person and then personalises her experience. Going through breast cancer allowed her to make more time for herself. She claimed her experience as a time to focus on herself. Mary in her reflections below, speaks about her new attitude and lifestyle which she adopted through her experience of breast cancer.

You don't worry about small things anymore. You more or less accept it. I am also very sensitive when it comes to my body. I watch what I eat and whatever. (Mary)

Yes, I became more considerate. You know sometimes you go and have fast foods which you should not have. (Mary)

Mary believed that one should not have fast foods. She adopted a worldview where healthy eating was important because it ultimately goes into her body. One needs to reflect on the context within which these women are experiencing these emotions and new lifestyles. Breast cancer attacks the body, therefore these women believed that looking after their body now was vital. This experience allowed them to realise the importance of their health and wellbeing. Mary goes further when she tries to make sense of why she has breast cancer which brought to light her new perspective adopted.

My lifestyle, I work shifts, not looking after what I eat, worrying about things, Yes of cause it can affect your health but I mean even people who go to gym and eat right they still get cancer. I think the way you live contributes to getting cancer. I don't take work so seriously anymore. I wanted to get a better position, a career. Now I don't want that anymore. I want to be more flexible and fly around. (Mary)

Mary appears to be certain that a less healthy lifestyle, work schedule and concerns can affect one's health but then reflects on the fact that healthier people gets cancer as well which then makes her "think" that the way one lives contributes to getting cancer. Additionally, her goals in life changed as well as her attitude towards her job which she identified as a factor that can affect one's health. Mary refers to "her" lifestyle but then states that it can affect "your" life not "my" life. It may be difficult to process that her actions or way of life affected her health. She then counteracts this thought by stating that people who live a healthier lifestyle gets diagnosed with breast cancer. Similarly, Gaby reflects on her health and how she feels about her body:

I feel healthy. I feel fit. Sometimes I think our bodies are like a machine, so it can break or give in at any time. Also makes me realise how vulnerable my body is. Appreciate my body more, and looks after myself more. (Gaby).

Gaby refers to bodies as machines to highlight the point that it can break or that something can go wrong. Through her experience, she realised the vulnerability of her body which ultimately allowed her to appreciate her body more. Additionally, Ruth reflects the changes that took place through her experience of breast cancer:

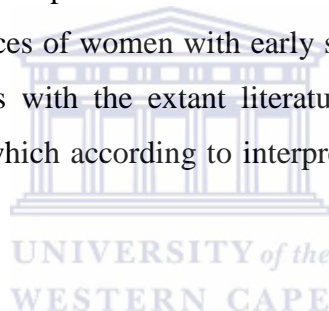
I think it's definitely brought me closer to god, so definitely from a spiritual perspective it definitely has changed me um, I think from a family perspective also I mean I was always here there everywhere for everybody and I realised that my family comes first, my best friend is my husband. I think you have new appreciation for, (pause) you know the saying goes you find out who your real friends are through tough times, and that is really so real, it really is very visible. I think just a new level of understanding me and what I need to survive to make this journey easy for myself and my family. And just living each day to the fullest. I always lived that way but I think what changes now is living each day to the

fullest with people that really matter which is my family. Also not sweating the small stuff. If the house is not clean, don't scream and shout and rant and rave it's not that important. What is important is for me to sit down and draw with the kids for them that's more important at that point in time. I'm not saying live in a pig sty but I'm saying maybe wait until they go to bed before you put things away. (Ruth).

Ruth, through her experience of breast cancer learned a lot. It deepened her spirituality and allowed her to get a better understanding of who she is and what she needs. The most important aspect for Ruth appears to be relationships. Through her lived experience she realised who were the important people in her life and realised that she should live each day to the fullest with these people in her life. The small things such as cleaning did not take precedence anymore, she valued the time she spent with her family much more.

4.7. Conclusion

The results of this study has been presented in this chapter above. It sheds light on the emotional and physical experiences of women with early stage breast cancer. The following chapter integrates these findings with the extant literature and the various context these participants find themselves in which according to interpretative phenomenology influences their experiences.



CHAPTER FIVE

DISCUSSION

The aim of this study was to explore the subjective lived experiences of women between the age of 30 and 40 with early stage breast cancer undergoing treatment. With this aim in mind, two objectives were set out. The first was to explore the emotional experiences of these women and the second was to explore how they perceive their bodies through their experience of early stage breast cancer while undergoing treatment. Through the analysis process, five themes emerged meeting the aim and objectives set out. The five themes are namely: *receiving the diagnosis, effects of treatment, silent suffering, coping strategies and turning point.*

The theoretical framework conceptualising the study is interpretative phenomenology. Through this framework, I aim to present the nature and meanings of the experiences of participants, to interpret the results in relation to the various contexts of participants as well as relevant literature. The experiences of participants according to Lopez and Willis (2004) are influenced by conditions of their daily lives. I aim to reflect the double hermeneutic of the IPA approach in that the findings and discussion conveys my interpretation as the researcher of the participants' interpretation of their experience (Smith *et al.*, 2009).

In its entirety, the five themes identified illuminate the essence of the emotional and physical experiences of women with early stage breast cancer. The diagnosis of breast cancer proved to be an unexpected one for certain participants. Two thirds of participants described feeling a level of shock and/or fear when reflecting on receiving their diagnosis. While certain participants only experienced these emotions, for others, the experience of shock translated differently whereby they wondered why they were diagnosed with breast cancer. On the other hand, certain participants did not question their diagnosis but rather used the prevalence of

breast cancer and their spirituality to make sense of their diagnosis. Overall, conversely to most studies such as the study conducted by Costa-Requena, Rodriguez and Fernandez-Ortega (2012) where a decline in quality of life and psychological well-being is observed, participants in this study did not report any severe distress, mainly shock and fear regarding their diagnosis and the uncertainty of the journey ahead. Furthermore, emotional difficulties arose when experiencing the physical alterations from breast cancer treatment. Reacting with a shock and fear stems from various influencing factors and indicates that optimistic bias exist. These women fall within a younger age group which contributed to their response of shock, fear, disbelief and a lack of expectation of a breast cancer diagnosis due to its prevalence amongst older women. Furthermore, this was evident amongst the doctors that were consulted by participants. They did not suspect breast cancer due to the age of certain participants. This was however evident for the “younger” participants in the sample. Additionally, most participants viewed the diagnosis of breast cancer possible when breast cancer or cancer was a part of one’s family history. Therefore when no family history existed, the nature of a breast cancer diagnosis was unexpected and characterised by shock. Furthermore, for one participant, motherhood took away any suspicion of breast cancer. This sheds light on the assumptions participants had regarding risk factors related to a breast cancer diagnosis. Although the prevalence of breast cancer is widespread, women tend to feel relatively invulnerable to breast cancer (Welkenhuysen, Evers-Kiebooms & Decruyenaere; Fontaine & Smith, 1995). Welkenhuysen, Evers-Kiebooms & Decruyenaere in their study found that optimistic bias does exist with respect to an individual’s perceived personal risk of developing breast cancer

Furthermore, for some, informing family members about their diagnosis made them fearful. Notably, these participants had no partners or children. Their family was therefore their priority and the first aspect they thought of when receiving their diagnosis. Making sense of the worlds of participants entails a consideration for their contexts. When wondering why they were diagnosed with breast cancer, participants had an expectation that it can happen to other people but not to themselves which may stem from these aspects discussed above. There was a disbelief surrounding their diagnosis.

Corbin (2010, p. 105) states that “why me” is a phrase often heard by physicians caring for patients with newly diagnosed breast cancer. She states that patients often say the following:

“I did everything right, I exercised, I ate well, I took supplements, I tried to minimize stress, I went to church. Why did I get breast cancer?” Corbin (2010) asks an important question: “What is the evidence that doing things *right* prevents breast cancer?” This question allowed me to reflect on the responses received by participants in relation to nutrition and lifestyle. Participants after their diagnosis changed their lifestyles and had a desire to eat better and take care of their bodies. This may imply that they may have believed that they were living life the *wrong* way in terms of nutrition and lifestyle. One participant in this study stated that she lived a healthy lifestyle and interestingly, she was not one of the participants who questioned her diagnosis. Corbin (2010) makes reference to an interesting study that she states was published in 2005 which had a sample of over 450 patients with breast cancer. Participants were asked why they thought they had developed cancer. Results indicated that participants typically underestimated the importance of behavioural factors that are known to be associated with increased cancer risk, such as obesity and physical inactivity, while overestimating the importance of stress and environmental pollution (Corbin, 2010). Results in this study however speaks to the latter point in that participants made reference to behavioural factors such as exercise, eating habits and overall lifestyle choices. According to Corbin (2010) nutrition has been explored as a risk factor for cancer development, progression, and recurrence. Women’s interests have been piqued, as diet and dietary supplements are potentially modifiable and thus give women a sense of control over the disease. This is evident in the experiences of certain participants who after their breast cancer diagnosis choose to change their eating habits.

Breast cancer patients have been identified as at risk for affective disorders (Campos *et al.*, 2012). Anxiety, fear, anger and depression are emotions experienced during diagnosis and treatment (Clay, 2013). Breast cancer experiences in the studies conducted by Perreault and Bourbnais; Taha *et al.* (2012); Grageset *et al.* (2011) as well as Joulaee *et al.* (2012) found that fear, anxiety and uncertainty was characterised by various factors such as body image, family adaptation, social stigma and ultimately death. Grageset *et al.* (2011) found that death anxiety was clearly apparent among participants. They found that their existence, values and basic needs for meaning and purposefulness were threatened. Grageset *et al.* (2011) states that struggling with uncertainty and existential threats may lead to increased awareness of values in life. This was evident in the experiences of the participants in this study. Instead of experiencing severe distress as documented in the literature, participants found meaning through their experiences and had a greater appreciation for life. Although a vast amount of

literature highlights the emotional impact of breast cancer such as depression and anxiety, studies found that women experience having a new love for life (Clay, 2013; Horgan *et al.*, 2011). Participants experienced a turning point which gave meaning to their experiences. While this was a similar experience, it differed in certain ways. Turning points involved either one, a few or all of the following perspectives adopted namely; prioritising themselves, living a healthier lifestyle, spending more time with family and appreciating the small things in life. A study conducted by Lam and Fielding (2003) found that the ever-changing interruptions imposed by breast cancer over-rode their previous assumptions about life and ultimately forced the women to re-organize and re-define their lives. Death appeared to be more imminent for their participants however, these women nevertheless construed positive meanings from their illness, which according to Lam and Fielding (2003) is consistent with the western literature and is evident in the results of this study. Lam and Fielding (2003) state that positive meanings may reflect an adaptive strategy designed to maintain a positive perception of the self, as well as the life purpose or a simple re-framing of priorities. Additionally Inan, Gunušen, and Ustun, (2014) found that positive changes took place in women's' lives due to their breast cancer diagnosis. They found that facing the reality of death makes the women question life and realize that everyday routines, habits, and values lose importance. Through this process, new meanings of life are formed. Similarly, Cebeci *et al.* (2012) in their study found that after a cancer experience, their worldview changed and positive changes took place. Drageset *et al.* (2011) notes that the appreciation of life is stimulated when meaning can be found in situations of great uncertainty. Participants in their study reflected on their priorities in life. Their cancer diagnosis reminded them to appreciate life and live each day to the fullest. These results are evident in the results of this study. Additionally this relates, in certain ways, to the study conducted by Henselmans *et al.* (2010). Participants reported positive outcomes which relates to the large group of women in their study who reported high optimism, strong support systems and minimal physical complaints. Patel *et al.* (2014) in their study found that participants viewed life as too short for them to worry about trivial things, and although it was second nature for them to think of family before themselves, they learned that it was also important to prioritise their own well-being. This stemmed from a commonly held belief that breast cancer was a result of being stressed led many women to try to avoid undue worry. This was evident in this study, although certain participants stated that they would prioritise their needs, silent suffering was evident.

Drageset et al. (2011) in their study found that most of the women had difficulties accepting their diagnosis while feeling healthy. They felt their health status had changed overnight and that they had become affected by an uncontrollable and unpredictable disease. They experienced a sudden transition from a state of wellness to a state of illness and disease. Most women in this study did not expect a breast cancer diagnosis due to their age, no family history of cancer, being a mother and feeling healthy. Certain participants thus felt betrayed by their body because they felt healthy but that was not the case. In order to cope with the experiences that come from a breast cancer diagnosis, participants relied on various sources for support such as their spirituality, family, the self as well as friends. Spirituality and religion was found to be a major source for coping. Spirituality appeared to provide participants with a certain level of peace regarding their experience. Believing that God has a plan for them allowed them to deal with the difficult situation they found themselves in and added meaning to their experiences. In addition to spirituality, a positive attitude and outlook on life contributed to an easier experience of breast cancer for certain participants. These results relates to Patel et al. (2014) who found that women already held strong religious beliefs which strengthened after their diagnosis. They felt that this was instrumental in helping them to understand and help them cope with their diagnosis. Additionally, Inan et al. (2014) as well as Cebeci et al. (2012) in their studies found that religion and spirituality played an important role in the lives of participants. Women either viewed their diagnosis as a test from god or as in this study, deepened faith in God. Spirituality has been viewed as an important psychological resource that improves coping skills, adaptability, and quality of life (Harandy *et al.*, 2010). For one participant, experiencing less favourable emotions such as anger and hatred was recognised as a weakness that was counteracted by a reminder that there are reasons for one's experience. There was an expectation that one has to be strong, think positive and move forward. Similarly, Women in the study conducted by Beatty et al. (2008) were expected to always be strong and manage others. When women experienced levels of sadness, this was viewed as adopting a negative attitude towards a situation which was frowned upon. While certain participants focused on staying positive, one participant due to her experience of breast cancer, found it difficult to be positive and offer encouragement to others within her work environment. Working in theatre while going through breast cancer treatment made it difficult for this participant to stay positive. The context in which participants' feel certain emotions is thus important to consider. In relation to coping, support from family, friends and work colleagues was evident in this study. For certain women, even

though support was available, they either believed it was not one of their needs or preferred relying on themselves.

Drageset et al. (2011) state that social interaction may help by giving both information and emotional support. This is a finding which relates to the results in this study. Social interaction for certain participants acted as a coping mechanism and provided participants with a sense of purpose. Their experience of breast cancer found in this study enabled certain participants the ability to provide advice and encourage others to go for check-ups. Notably, the importance of finding meaning in illness that might strengthen coping abilities is described previously. According to Folkman and Greer (2000), as stated in Drageset et al. (2011) meaning based coping helps individuals to relinquish problems and enables them to pursue goals and formulate new ones, make sense of what is happening and appraise benefits whenever possible. Some of the women even managed to reflect upon the positive sides of having breast cancer and were convinced that it would increase their personal mental strength, which reflected appraisal of the opportunity of a positive outcome.

Even though the majority of participants refer to the various sources of support they received through their experiences, the breast cancer journey has been characterised by silent suffering. The silent suffering was due to a number of factors. Participants wanted to remain strong for family members which in turn resulted in feelings of loneliness. This was the case when participants were married with children. Time was noted as a factor influencing the display of emotions. One participant noted that there was no time to cry in front of family members which reflects the busy life of a mother and wife. Cancer was identified as something that is not spoken about. A participant noted that doctors would use an abbreviation when talking about it in order to make patients feel more comfortable. It was noted that people in general would also not speak about cancer. This could therefore have influenced the way in which women dealt with breast cancer. The silent suffering stemmed from an expectation to not discuss aspects related to cancer. Furthermore, other reasons why women would not confide in family, friends or work colleagues is because they believed that people who did not go through the same lived experiences as they did would not understand their journey. In the study conducted by Drageset et al. (2011), having to inform significant others about their diagnosis was a major burden for most participants. Some kept their diagnosis to themselves to prevent significant others' distress. Drageset et al. (2011) makes reference to other studies and states that women often feel uncertain about communication

with close persons about their diagnosis. In this study, informing parents appeared to be a major concern for two participants. One of these participants noted that they did not want their parents falling ill due to stress from their diagnosis which emphasizes the point made that participants will put the needs or wellbeing of others before their own. Furthermore they found that participants tried to lighten the burden on their family by choosing their words carefully and by being strong, which implied depriving themselves of expressing their own reactions. Giving priority to family members' emotional needs may either have imposed a burden of self-control, or protected them from being overwhelmed. The two dimensions lived by women experiencing breast cancer found in the study conducted by Goldblatt et al. (2013) is evident in this study. Women kept their emotions to themselves and tried to display a happy exterior for family members. Another reason why participants did not express their emotions is because they believed that no one will understand what they are going through. Furthermore, family members of participants in this study could not handle the physical effects of breast cancer treatment. This relates to the study conducted by Beatty et al. (2008) and Banning and Tanzeen (2013) where family members could not handle the diagnosis of their loved ones. Participants in their study had to therefore keep up a front which resulted in decreased support and more distress. However within this study, the support was limited due to the reasons mentioned however, spirituality was a major coping factor allowing distress to be limited.

With regards to treatment, two participants had mastectomies of one breast as well as chemotherapy; three participants had lumpectomies, two of which had chemotherapy while the other had radiation therapy. The last participant had chemotherapy with a scheduled mastectomy followed by radiation therapy. Experiencing chemotherapy was difficult due to the expectation of physical changes. Starting treatment made the diagnosis of breast cancer a reality, as it provided "evidence" of the illness. Participants expressed a deep concern for the loss of hair. While most participants dreaded the start of chemotherapy, one participant expressed that she was fearful of the loss of hair. However in addition to this fear experienced, she stated that she was excited to start chemotherapy in order to start fighting her illness. On the other hand, one participant struggled immensely with the side effects and loss of hair. She considered dying a better option compared to what she was dealing with physically and emotionally. To deal with the hair loss and cold, certain women utilised wigs. On the other hand one participant wanted to show others that one does not require a wig to be pretty. For her, the loss of hair did not affect her however the stares she received from people

due to her physical changes reminded her that she looked different. Additionally, she experienced new ways of exploring her beauty through scarfs, hats and big ear-rings.

Participants in this study experienced shock and fear when diagnosed with breast cancer. Sadness, insecurities and difficulties arose before treatment due to the anticipation of physical changes, during treatment and when these physical changes took place. Tuffin, Hamid and Blake (2014) confirms this by stating that the notions of body image are complex and can encompass perceptual, emotional and behavioural aspects of experience. In general, body image is a widespread preoccupation. Body dissatisfaction is so prevalent among women that it was coined 'normative discontent' by Rodin, Silberstein, and Striegel-Moore in 1984 (Tuffin *et al.*, 2014). Body image is already such an issue amongst women without a breast cancer which diagnosis which is known by its physical effects. Harcourt and Frith (2008) highlight that limited research focused specifically on the personal impact of an altered appearance during chemotherapy treatment. Their study explored women's experiences of an altered appearance during chemotherapy. Results from their study indicated that the appearance of women acts as a visible indicator of their disease status to both themselves and others. Similarly to the results in this study, Harcourt and Frith (2008) found that hair loss is seen as a confirmation of identity as a cancer patient.

Most of the concerns and emotions regarding mastectomies came from women who did not undergo mastectomies. All three women who did not have a mastectomy reflected on the possibility of having to undergo one and how they feel about it. Two of these three women viewed their breasts as a very important part of their womanhood/femininity. Due to this factor, these women did not consider having a mastectomy. They questioned their ability to cope if they should go through with the operation. The third participant viewed the possibility of the removal of her breast as unimportant and viewed living as more of a priority. However, she was happy that she did not have her breast removed. Having scars for her was not as bad as removing the whole breast. It's interesting how each lady who did not have a mastectomy reflected on these issues and how they might feel about it. On the other hand, from the two participant who had mastectomies, one of the participants did not reflect in detail about her mastectomy but rather mentioned that she had it done and focused on the loss of hair she experienced. This, for her, may have been more of an issue than the removal of her breast. The other participant who also had the mastectomy was concerned about what others may think about her having only one breast. She dealt with having only one breast by making light

of her situation. The participant who had a scheduled mastectomy was unsure of how she felt regarding the upcoming operation. She was, however, worried about what the scars may look like. So in turn her physical appearance was a concern. According to Lam and Fielding (2003) the breast is given a sexual dimension in the tabloid media, but women in their study appeared to value the breast much less as a sexual, feminine or even functional feature than in western culture. Women in Hong Kong seldom breast feed and when asked about the impact of breast loss on their sexual relationship, none of the women in this study expressed significant concern about their sexuality per se. Moreover, none felt that losing their breast would have a detrimental effect on their marital relationships. These results differ to the results found in my study. However, for one participant in this study breast feeding her children was one of the reasons why she didn't suspect a breast cancer diagnosis. There were concerns surrounding sexuality and the acceptance of their new physical appearance by partners. One participant noted that her husband would be less affectionate. This may be due to a fear of hurting her or because he might not know how to deal with the situation. In this case the participant did not have a mastectomy however one participant who did wondered how she will be accepted by a future spouse. Furthermore, physical change had an effect on participants but also on family members and society. The effect of physical change on family members in turn affected participants. With regards to society, participants reported that they would get stares from "people" which they found to be very rude. All participants who had children reported that the physical effects of treatment affected their children. It all revolved around "what can be seen". Wigs were utilised to make the process easier for family members. The physical changes experienced by participants gained stares from general people in society which reminded certain participants of their illness and increased their level of security within themselves. Similarly, Patel et al. (2014) in their study found that people would make inappropriate remarks which resulted in women wanting to keep their diagnosis private. Harcourt and Frith (2008) note that despite increased knowledge and openness to discuss cancer over recent years, the disease is still associated by many as being stigmatized. Some of the women in their study felt stigmatized because they had cancer and, secondly, that they were visibly different. It appears that from the emotional and physical experiences, participants would put the needs of others before their own. Harcourt and Frith (2008) found that women would try to safeguard other people's feelings and also deal with their own reactions to the situation they found themselves in. Some women had a sense of obligation to try and make things as easy as possible for other people. For example, the effort directed

towards camouflaging the changes to appearance through the use of wigs, scarves and hats was partly in order to protect other people's feelings.

Lam and Fielding (2003), in relation to the effects of treatment, found that the visible evidence of illness, such as hair loss and weight gain threatened participants' sense of self significantly more than breast loss or treatment side-effects like nausea and vomiting. This is an important point as experiencing side effects was one area of the treatment process that participants reported on. Conversely to wider literature and in relation to Lam and Fielding (2003), the side effects experienced by the majority of participants were minimal and in other cases not evident at all. One participant believed that one's mind-set influences your physical experience while another viewed herself as blessed for not having any bad side effects. Another participant however stated that she got very sick from chemotherapy. In combination with the loss of hair, these factors made her feel like she would rather die than go through with treatment. Experiencing side effects therefore contributed to the way she felt.

Harcourt and Frith (2008) notes that researchers in the field of appearance and visible difference have tended to focus on the impact of those that are permanent while less attention has been given to those that are temporary. They found that the impact of supposedly temporary changes to appearance is akin to the reports given by people with a permanent visible difference. Importantly they state that their findings suggest that the psychosocial impact is no less just because the changes are temporary. This is an important point highlighted by Harcourt and Frith (2008) which is relevant to the results found in this study.

Age is an important factor to discuss since it forms a big part of this study and filters through the experiences of participants. The age of participants relates to the stage in life in which they find themselves. This involves being a wife, mother (mostly to young children), being single, not having children yet are a few of the factors one needs to take into consideration when exploring the experiences of participants. Throughout the interviews, age was not directly reported on however some of participants made reference to certain experiences where age played a role. One participant noted that when going for treatment she felt out of place in the waiting room because she was the youngest person there. It was a world where she felt as though she did not belong. Similarly, a participant mentioned age when referring to the shock of her diagnosis while another noted that she felt older due to the loss of hair. For participants' in this study receiving a breast cancer diagnosis as well as the loss of hair is

associated with an older individual. Furthermore the concern regarding fertility and future life partners was a concern. The age of participants therefore gives rise to specific concerns.

CHAPTER SIX

CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

6.1. Conclusion

This study set out to explore the subjective lived experiences of women with early stage breast cancer undergoing treatment. The general literature on this subject and specifically in the context of South Africa is limited. The emotional difficulties experienced by participants relied mostly on the physical effects of breast cancer treatment. The physical change was tough to deal with. For some, their breast cancer journey was a lonely one. This was influenced by the role as a mother, wife or daughter which resulted in participants protecting family members from their emotional state and physical changes. An additional influence stemmed from the belief that no one will understand the journey that they are on and therefore participants would not express their emotions. However, the reliance on spirituality and positivity was a major coping strategy while the reliance of family and friend were either not needed or limited. These were the choices of participants due to the factors mentioned above such as protecting family members, considering the needs of family members above their own and believing they won't understand. The physical changes that took place due to treatment affected participants due to the connection certain body parts such as breasts and hair has with femininity and womanhood. A breast cancer diagnosis therefore threatened their

identities which are associated with these body parts and the roles they allow women to play. It is vital to understand these aspects within the context that they occur.

Although all women had early stage breast cancer and were in a specific age range, their context differed in that some were married or divorced while others were still single and some had children while others did not. These important aspects shaped the experiences of participants and needs to be considered when exploring the breast cancer experiences of women. A deeper understanding of this phenomenon has been obtained. It is important to gain this level of understanding regarding the experiences of breast cancer especially in the South African context to ultimately inform interventions. Even though certain participants noted that their journey cannot be understood, they provided me with the opportunity to access their worlds and try to obtain an understanding of their lived experiences.

6.2. Limitations

This study is subject to certain limitations which should be noted. As noted earlier, difficulties arose when recruiting participants. This may be due to a combination of factors such as the specific profile set for the sample, accessing participants not being established way in advance, how participants were being accessed which ultimately reflects on the sampling methodology used. Due to the fact that access was denied at certain oncology units, the sampling methodology had to change. Given the relatively specific and small sample size as well as the non-probabilistic sampling methodology employed in this study, statistical generalizability to the larger population is not applicable. Additionally, the stage in which participants find themselves in their lives is something to consider. Even though all participants are in a specific age range, they were in different stages in their lives. Some participants were married while others were single. Certain participants had children while others did not. These factors influenced how these women experienced breast cancer. This study included only women aged between 30 and 40 with early stage breast cancer. Therefore, these results may not be generalizable to older women or to women diagnosed with more advanced breast cancers, who often have different treatment experiences. Differences in prognoses between women with early-stage and women with more advanced breast cancers would also be expected to be associated with differences in concern about

progression between these two groups of patients. Future research might examine such differences.

As noted in my reflections, certain participants stated that people will not understand unless they too have been diagnosed with breast cancer. However, as noted previously, participants willingly participated which indicates that they wanted to voice their stories and provide insight to their experiences.

6.3. Recommendations

It is evident, from the results found in this study that further research is needed in the area of younger women's experiences of breast cancer especially in South Africa. In addition, open communication between patients and family members should be encouraged. The inclusion of a special time to discuss how the family is coping with the breast cancer treatment; and the encouragement of the woman and her family to use the resources provided by health professionals are important aspects to cover. Counselling performed before treatment could be beneficial as the lack of understanding and the particular concerns and needs of women diagnosed with breast cancer, ultimately affects their health care experience (Coyne & Borbasi, 2009). In addition to this, women should be encouraged that their wellbeing is just as important as their loved ones and that this should not only be acknowledged but put into practice. Additionally, it is important for health care professionals, family members and friends to understand that the experience of breast cancer diagnosis and treatment for younger women is made more difficult because of their biological status and the complexity of the roles traditionally associated with this time of life, education and further research is needed. With regards to the stigma experienced by participants due to their physical appearance, instead of simply raising awareness, the mind-set of people needs to change and the ideals associated with the perfect female body. The results of this study indicates that breast cancer is not only a threat to a woman's life but also a violation of her understanding of herself as a woman. The meaning of these results for feminist psychology is vital as it is evident that there remains a high value on breasts and hair as a part of the female form and persona. As stated by Kasper (1994, p. 264) "through the process of female socialisation women come to believe that to lose a breast is to lose one's identity and sense of self as a woman". Too much attention is still on the woman's body which ultimately influences the experience women has of diseases.

Consistent with previous research, women identified fears about infertility, or not being able to have children because of concerns about future cancer recurrence. These concerns highlight the stressors associated with being diagnosed with cancer at a young age. Interventions that aim to assist these women need to specifically target these areas of concern. In particular, supportive interventions that assist women to manage their fears in a helpful way and to understand how children cope with parental illness and loss may be important (Hooper-Zahlis and Lewis, 1998).

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APPENDIX A: INFORMATION SHEET

Project Title: Subjective lived experiences of women with early stage breast cancer in Cape Town.

What is this study about?

This is a research project being conducted by Nicole Scullard at the University of the Western Cape. I am inviting you to participate in this research project because your participation in this study may provide me with a better understanding of the subjective lived experiences of early stage breast cancer. The purpose of this research project is to explore the emotional experiences of women with early stage breast cancer and how these women perceive their bodies through their experiences while undergoing treatment.

What will I be asked to do if I agree to participate?

You will be asked to be a part of an interview where I will ask you questions regarding your emotional experiences and body image in the context of your breast cancer experience. Approximately 1 hour of your time will be requested for the interview. The interview will be conducted at a mutually convenient location. Your participation will be greatly appreciated.

Would my participation in this study be kept confidential?

I will do my best to keep your personal information confidential. To help protect your confidentiality, the research process is guided by strict ethical considerations of the University of the Western Cape and will be adhered to at all times. You will be asked for permission to record the conversation during the interview. The recorded conversation will be used for the purpose of data analysis only. All your personal detail will remain confidential. To ensure confidentiality, I will ensure that audio files and interview transcriptions will be kept in a safe place, and the data will be saved in password-protected computer files.

When I write the report about this research project, your identity will be protected to the maximum extent possible by using pseudo-names.

Confidentiality will be maintained at all times. If this research study is published, your identity will be protected to the maximum extent possible.

What are the risks of this research?

There may be some risks from participating in this research study. As a participant, you may experience emotional discomfort during the interview. If you feel distressed during the interview, you may indicate this to the researcher and counselling will be made available for you.

Is any assistance available if I am negatively affected by participating in this study?

If the interview results in any emotional discomfort, counselling will be arranged by the researcher. You may withdraw from the study and will be immediately provided a list of contact details of mental health care providers who will be available to provide you counselling service. A follow up phone call or a visit will also be available from the researcher to maximise the protection from any emotional harm or unpleasant feelings.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about breast cancer and how women experience it emotions and how they view their bodies. We hope that, in the future, other people might benefit from this study through improved understanding of how younger women experience breast cancer. The results from this study could aid the therapeutic process of women with breast cancer by gaining a deeper insight into the root of their emotional experiences and body image.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify

What if I have questions?

This research is being conducted by Nicole Scullard at the Psychology department at the University of the Western Cape. If you have any questions about the research study itself, please contact Nicole at: 0769141737 or Email: scullard.nicole@gmail.com

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Head of Department:

Dr M. Andipatin
Department of Psychology
University of the Western Cape
Private Bag X17
Bellville 7535
Tel: 021 959 2283/2454
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Dean of the Faculty of Community and Health Sciences:

University of the Western Cape

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Bellville 7535

This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.



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APPENDIX B: INTERVIEW SCHEDULE

1. Greeting and demographic information completed.
2. Consent form and the building of rapport by getting to know the participant and explaining why they were chosen for this study as well as the importance of voicing their experience with breast cancer.
3. **Questions for the semi-structured interview**
 - How did you feel when you received your diagnosis?
 - How did the diagnosis make you feel about yourself?
 - What feelings do you experience while undergoing treatment?
 - When you look in the mirror what do you see?
 - How do you feel about your body?

- What type of treatment of surgeries did you undergo? How did those affect you both emotionally and physically?
- What would you like others to know about your emotional and physical experience?



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APPENDIX C: CONSENT FORM

Title of Research Project: Exploring the subjective lived experiences of women with early stage breast cancer in Cape Town.

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way. I understand that my input will be recorded digitally. My questions about the study have been answered and I hereby give my consent to be a part of this research project as well as to use my input in writing for publication.

Participant's name.....

Participant's signature.....

Witness.....

Date.....

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

Study Coordinator's Name: Nicole Scullard

Cell: 0769141737

Email: scullard.nicole@gmail.com



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