

**Women's lived experiences of the breast cancer
trajectory:**

**The waiting period for treatment and the impacts on
feminine identity**

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Abstract

Breast cancer, according to research, is diagnosed in approximately one in every twenty-nine women in South Africa. Differences in gender, race and class produce disparities in health care, subjecting lower class women to lengthy waiting periods between diagnosis and treatment. Present research studies on breast cancer predominantly use quantitative methods. To understand women's lived experiences of the breast cancer trajectory this study explores experiences encountered during the waiting period, as well as the impacts of breast cancer and its treatment on feminine identity. For this a qualitative method was applied. Semi-structured, in-depth interviews were conducted with five black and coloured breast cancer patients residing at two of CANSA's care homes. Participants varied in age and phases of treatment, were all married or widowed, had minor dependants, and had all travelled from distant and outlying areas. Based on a thematic analysis, six themes emerged from the data collected. These included: First experiences of cancer in the body; breast cancer and waiting periods from the patient's perspective; sources of support; meanings and perceptions of being a woman; conceptualising disease, and patients' needs. The analysis illustrates the importance of researching women's lived experiences and highlights that these need to be understood within a framework of socially constructed notions of gender, race and class in order to improve breast cancer treatment and psycho-social care.

Chapter 1: Introduction

The broad area of interest for this thesis emerged after discovering a research topic on UCT's Knowledge Co-op website, submitted by the Cancer Association of South Africa (CANSA). Together with the Knowledge Co-op and CANSA, it was agreed that this research would be aimed at exploring the experiences of breast cancer patients awaiting treatment. By applying a gendered framework through which to view these experiences, emphasis was also placed on breast cancer survivors' conceptualisations of feminine identity and how their breast cancer and treatment trajectory impacted on these.

The literature reviewed suggested that most research has typically been conducted on white, upper class women, and that women of colour and of a lower social ranking often experience lengthy waiting periods between a breast cancer diagnosis and various treatments. As such, it was clear from the beginning of this research process that issues of gender, race and class were vital to producing relevant knowledge around breast cancer survivors' experiences in an attempt to develop a better understanding of these experiences and to recognize which areas of psycho-social care may need improvement.

Section two presents a literature review, uncovering dominant themes in breast cancer research and feminist studies. These include the following: social constructs and theorising gender; gender in the medical world; invisibilising the female body; a brief overview of the Women's Health Movement; breast cancer - a social and medical paradox; the disparities in cancer care and breast cancer in the South African context; what it means to receive a breast cancer diagnosis; the illness trajectory; heterogeneous experiences of conceptualising illness; women coping with a breast cancer diagnosis; and finally, emerging implications for this dissertation.

Chapter three presents the background to developing this project. It provides a brief introduction to CANSA and CANSA's research interest, as well as my personal experience and reasons for my curiosity on the topic. This chapter also reveals the research focus and gives a brief rationale for linking breast cancer with feminist studies. Finally, the main- and sub- research questions are highlighted, illustrating the intent to understanding the links between gender, social constructions of femininity and the experiences of breast cancer.

Section four explores the chosen research methodology, covering areas such as methodological framework and feminist theory to illustrate the importance of taking gender seriously and to support my decision to use semi-structured interviews to generate data. This section also highlights research methods used, emphasizing topics such as selection criteria, recruitment, data collection and data analysis; Ethics; positionality; and finally possible limitations and challenges posed by the chosen methodological framework are also discussed.

Chapter five presents my research findings and demonstrates my interpretation of five women's experiences through a thematic analysis. Five dominant themes emerged and included first experiences of finding cancer in the body; breast cancer diagnosis, treatment and waiting periods from the perspective of patients; sources of support; meanings and perceptions of what it means to be a woman; conceptualising disease and cancer; as well as patients' unmet needs and unanswered questions.

This is followed by chapter six, which involves a discussion linking these findings to previous research results, and to my research questions. This section also considers new insights and previous findings as well as ideas that appear to be challenged by these findings. In addition, it emphasizes that this research project is relevant, and that its focus on the gendered experiences of women breast cancer patients is what makes it important as 'new knowledge' in Gender and Transformation.

Finally, section seven provides a conclusion in which the overall research process and findings are summarized, providing a reflection on my journey as a feminist researcher and includes suggestions as to how this research could be taken further in the future. It highlights that understanding and being conscious of women's gendered experiences, and not simply the physical healing process, are vital to improving breast cancer survivors' experiences at all stages of treatment, and in advancing social transformation.

Chapter 2: Literature Review

This literature review has examined various texts and studies in an attempt to understand previous research findings on the topic of breast cancer in women's bodies. It explores several key areas, including the social constructions of gender and femininities, gender and women's health from a medical perspective, and the silences that have prevailed around women's bodies. It also attempts to investigate disparities in cancer care, breast cancer prevalence in South Africa, what it means to receive and cope with the diagnosis, and how disease is conceptualised and embodied. This literature review concludes with a brief section on potential implications for health care.

2.1) Social Constructions

A central theme throughout much of the literature appears to indicate that people's fate does not seem to be of their own making, but rather that social forces dictate to the individual. It is society that defines social constructs and categories by setting unspoken rules and regulations as well as expectations. This is especially the case with regard to race, class and gender. Certain perceptions influence popular notions of these 'categories'. These include the idea that humans are separated into different groups depending on physical appearance, intelligence and culture, and also that these determine whether individuals are placed in a social space of inferiority or superiority (Marger, 2000). Furthermore, these constructs are not acted out separately, but rather contribute to a larger experience of 'being'. This is echoed in the following quotation: "lived experiences, social locations, and identities are, in various ways, conditioned by a matrix of power within which overlapping hierarchies of race, gender, and class are central" (Harrison, 2005, p. 230).

2.2) Theorising Gender

Gender is a social construct, continuously produced and reproduced through social interaction. The processes of becoming gendered are legitimated not only by the people we interact with on a daily basis, but also by larger social systems such as religion, culture, the law and science. Dominant categories are deemed to be the hegemonic standards, and these vary according to context and timeframe. The overriding and most influential avenue of upholding such gender ideologies is the complete invisibility of this process (Lorber, 1994).

Becoming gendered extends to the development of gender roles and identities, which ultimately categorizes individuals as either feminine or masculine, shaping women's and men's experiences of their social worlds (Lorber, 1994). In South Africa, as in many other countries, value is placed on dominant or hegemonic femininities, influenced by western notions and patriarchal expectations of beauty. These include a fair complexion, hailing from an acceptable social class, being heterosexual, and especially exuding sexual desirability to the opposite sex. Being feminine, thus predominantly translates into social ideals of having and maintaining a sexually pleasing physical appearance (Sanger, 2009).

Gendering processes are so common-place, that it is only when society's heteronormative assumptions and expectations of gender are not met, that we become aware of the ways in which gender is created. Lorber maintains that "gender signs and signals are so ubiquitous that we usually fail to note them – unless they are missing or ambiguous" (Lorber, 1994, p. 45).

2.3) Gender in the Medical World

Social stratification as a result of gender extends to the medical sphere (Lorber, 1994). Not long past, diseases suffered by women and their bodies were afforded very little public attention. Women's bodies have historically been perceived to be subordinate versions of the male form. Medical treatment of women would be sought and would frequently be administered without first consulting with, or sharing important information with, the woman concerned. As a result, women's involvement in the medical treatment processes of their own bodies, was typically marginalised (Olson, 2002 as cited in Schulzke, 2011).

2.4) Invisibilising the Female Body

Historically, the silence of health professionals on the topic of breast cancer as well as the perceived taboos around women's health, contributed to the invisibility of diseases affecting the female body. Prior to the 1940s, breasts were not a topic up for discussion in public conferences (Lerner, 2001 as cited in Schulzke, 2011) and information about women's health was kept strictly under wraps, essentially maintaining the power dynamics between authoritative male doctors and 'uneducated' female patients. Denying women information or support and guidance in terms of coping with their diseases ultimately rendered them completely dependent on medical physicians' or husbands' decisions with regard to their health (Gamarnikow, 1978 as cited in Schulzke, 2011). An underlying problem in keeping

women's breast health invisible and in treating health concerns within a paternalistic framework is that women's bodies are perceived to be "faulty, uncontrollable, and in need of paternalistic help" (Schulzke, 2011, p. 41).

2.5) Women's Health Movement

The traditional medical model assumes a paternalistic view to health and healing, which, given the second-class status of women, has until recently ignored or marginalized women's illness anxieties (Sherwin, 1992 as cited in Schulzke, 2011). Many activists have challenged this approach, giving rise to the Women's Health Movement. This establishment ultimately rejects medical paternalism and works towards social justice and rights so that women can claim greater control and agency over their own bodies. Additionally, this movement has set out to tackle access to healthcare, seeks out possible alternatives to the traditional medical model, and addresses dangerous medical practices often used on women's bodies (Downer, 2010).

The public attention now directed at women's health generally, is largely due to the advances in social awareness brought to light by activism around breast cancer. Its impacts and efforts have influenced government spending, as well as the focus and publicity of medical research (Schulzke, 2011). However, even though advances in challenging patriarchal views of treatment, and finding alternatives to the traditional paternalistic medical model, have been underway, women are still pressured to hide their suffering (Schulzke, 2011).

2.6) A Social and Medical Paradox

Cancer treatments and treatment facilities often tend to focus solely on the healing of a patient's body. It is important to bear in mind, however, that the experience of suffering is not limited to the body, and that it is not possible to separate physical suffering from psychological, emotional and social suffering. The suffering taking place in an individual is elevated by risks and fears of the loss of 'wholeness'. This is essentially compounded by social expectations of being gendered as a woman (Casell, 1992 as cited in Arman & Rehnsfeldt, 2003).

Social constructions link body parts such as the breasts as vital aspects of a woman's body and play an 'essential' role in identifying oneself as a woman. Societal perceptions connect breasts with being woman, being feminine (i.e. female identity) and with sexuality

(Yankaskas 2005, Demir et al. 2008, Helms et al. 2008 as cited in Drageset et al., 2010). Although most women agree that losing one or both breasts is preferable to succumbing to cancer, many also state their discomfort and concerns regarding their appearance after surgery. In addition, there is worry around what effect the loss of a breast or breasts would have on male partners, and how this would affect their self-esteem as women (Drageset et al., 2010).

For many, if not most women, the breast strongly denotes femininity and is therefore closely linked with sexuality and motherhood (Khan et al., 2000 as cited in Helms et al., 2008). Depending on a woman's stage of breast cancer, doctors recommend a variety of treatments, of which lumpectomies or mastectomies are common options. However, while this medical treatment process is justified in the name of health and survival, widespread social attitudes continue to pressure women into needing to obtain a standard of femininity and beauty, requiring both breasts to be intact (Schulzke, 2011). If the cancer is such that surgery is required, it is likely that a woman or her partner perceives it as a mutilation, regardless of whether a lumpectomy or mastectomy is performed, or whether one or both breasts are involved. Research has shown that the sense of loss is so pervasive that negative reactions of a psycho-social nature are common (Blichert-Toft, 1992 as cited in Helms et al., 2008). It is thus easy to speculate that such a surgery may affect a woman's sense of self to the point of an identity crisis, which implies that confidence, mood, self-esteem and consequently quality of life suffer (Helms et al., 2008). It goes without saying that the effect on the general family dynamics may be anything but positive.

Globally, breast implants and breast reductions are one of the most sought after surgeries in improving and enhancing beauty (Ott, 2002 as cited in Schulzke, 2011). While this shows that not only breast cancer patients deal with a breast complex, it is these patients in particular who are affected by feelings of being defeminized and desexualized (Zalon & Block, 1978 as cited in Schulzke, 2011). The paradox remains that while medically, breasts are considered to be removable, women must still attempt to preserve them if they want to fit into social norms and demands of femininity and beauty (Schulzke, 2011). As such, one might argue that breasts are gendered as one of the indicators of the femininity of women (Arman & Rehnsfeldt, 2003).

In light of these social pressures, breast cancer survivors commonly undergo breast reconstruction surgeries or obtain prosthetic breasts in an attempt to appear normal to the world. Lorde (1980 as cited in Schulzke, 2011) likens these actions to masking the reality of the situation. In addition, wigs and/ or prosthetics are not attainable by all due to differing financial circumstances and add to the already stressful burden of having to fund expensive treatments (Batt, 1994 as cited in Schulzke, 2011). This points to a societal view that there is only one 'true' feminine ideal and unsuccessful attainment ultimately results in a loss of social status of womanhood (Schulzke, 2011).

2.7) Disparities in Cancer Care

The intersections of class and race have also played a part in hiding some women's diseases better than others (Rosenzweig, Brufsky, Rastogi, Puhalla, Simon & Underwood, 2011). It is socio-economically disadvantaged women who struggle to obtain adequate medical resources and who remain hugely invisible in the literature and in case studies (Lerner, 2001 as cited in Schulzke, 2011). This disparity in health care is illustrated by an American study focusing on breast cancer, which explains that there are great differences between the survival rates of white, American women compared to those of African American populations (Rosenzweig, Brufsky, Rastogi, Puhalla, Simon & Underwood, 2011). Although it appears to be the case that white women have the highest incidence rates for breast cancer, it is black women who have the highest mortality rate as a result of breast cancer (Lantz, Mujahid, Schwartz, Janz, Fagerlin, Salem, Liu, Deapen, & Katz, 2006). Studies conducted amongst cancer patients in America illustrate that white women obtain more aggressive treatment than black women do and this essentially results in higher mortality rates for black women breast cancer patients (Blackman & Masi, 2001 as cited in Rosenzweig et al., 2011). Of great concern is the fact that the mortality rate for black woman breast cancer patients increased in the 1990s – the same timeframe during which breast cancer mortality rates were falling generally and specifically decreasing in white populations (Lantz et al., 2006).

2.8) The South African Context

Globally, breast cancer is the most frequently diagnosed form of cancer in women, and studies show that cancer mortality rates are highest for breast cancer patients (World Health Organization, 2008 as cited in Drageset, Lindstrom & Underlid, 2010). Increased breast cancer rates have been documented amongst various population groups in South Africa.

According to the Department of Health, breast cancer is the most prominent form of cancer in women in South Africa (2002 as cited in Dine, Austin & Armer, 2011). It has been recorded that 1 in every 29 women in this country is affected by this form of cancer (National Cancer Registry, 2001 as cited in Dine, Austin & Armer, 2011). In South Africa, the Asian population makes up 30% of cancer diagnoses. In the case of coloured women, this statistic drops to 25% of cancer diagnoses, and further to 18% in white women. Amongst black women, 17% of cancer diagnoses are identified as breast cancer (National Cancer Registry, 2001 as cited in Dine, Austin & Armer, 2011). It is argued that one of the reasons for increased incidence and prevalence of breast cancer diagnoses is due to urbanization and the many changes in lifestyle (including dietary changes and worsening living conditions) that accompany such a shift (Walker, Adam & Walker, 2004 as cited in Dine, Austin & Armer, 2011). However, it must be taken into consideration that knowledge and awareness with regard to breast cancer is perhaps more acute in urban areas and that statistics may be skewed due to factors such as whether or not individuals have easy access or exposure to clinics and/or mammography screening facilities (Lantz et al., 2006). Therefore, statistics presumably stating that breast cancer prevalence is higher in urban areas compared to rural areas needs to be questioned or researched more closely (Pillay, 2002 as cited in Dine, Austin & Armer, 2011).

It is of great concern that much of the literature on breast cancer overlooks women's lived experiences regarding their diagnoses. Additionally, it has been noted that there is a lack of research on the experiences of black South African women and their experiences of a breast cancer diagnosis (Dine, Austin & Armer, 2011). Authors such as Dine, Austin & Armer (2011) argue that it is vital to research these experiences in order to inform health initiatives and programmes concerning breast disease. Due to the fact that there are many discrepancies in healthcare policies on a national as well as on a provincial level, South Africa does not have an adequate healthcare program in place for breast cancer patients (Cancer Association of South Africa, 2008).

South African society in general is plagued by health care discrepancies, which negatively affects socio-economically disadvantaged groups. In this country, black South Africans make up the majority of this vulnerable population and access to health care facilities is more easily achieved by richer sections of the population and for those for whom transportation is not a predominant issue. Education and a lack of understanding with regard to breast health is another big part of the problem contributing to rising breast cancer rates in South Africa

(Bremer, Moore, Bourbon, Hess, & Bremer, 1997 as cited in Dine, Austin & Armer, 2011). Therefore, developing more adequate breast health programmes is essential in order to decrease risks as well as promoting better outcomes post-surgery, and encouraging health promotion (Dine, Austin & Armer, 2011).

2.9) Receiving a Breast Cancer Diagnosis

Few studies have conducted qualitative research on women's responses and experiences of a breast cancer diagnosis. The research that does exist, primarily includes quantitative evaluations of incidence, prevalence and symptoms (Lally, 2010). Obtaining a diagnosis for breast cancer is a stressful, demanding and traumatic event (Cordova et al, 2007 as cited in Drageset et al., 2010) due to the fact that affected women are suddenly confronted with a change in health and are faced with a life-threatening disease. As such, the event can elicit many emotional and psychological responses (Helms et al., 2008) and can cause physical as well as cognitive symptomatology (Cimprich, 1999). Symptoms frequently include pain, have an effect on movement, involve a lack of concentration, and often include anxiety and/or depression (Cimprich, 1999).

Studies suggest that waiting for information and results regarding diagnostic tests, obtaining the bad news of a breast cancer diagnosis and having to wait for treatment are three of the most stressful phases in the experience of being a breast cancer patient (Green et al., 1998; Gurevich et al., 2002 as cited in Drageset, Lindstrom & Underlid, 2010; Lally, 2010). In addition to these elements of the pre-surgery phase of breast cancer, patients are forced to meet countless physicians, are overwhelmed by complicated and extensive terminology, must undergo numerous tests and are forced to make life-altering decisions (Lally, 2010).

Women who are diagnosed with breast cancer and a co-morbid condition of depression are at a greater risk of relapse post-treatment and tend to have lower rates of adherence to antineoplastic treatments than women who have not been diagnosed with depression. These patients also tend to experience a decrease in their quality of life (Sharpley & Christie, 2007).

Furthermore, studies appear to indicate that risks for breast cancer increase with age and that 77% of breast cancer patients are over the age of 50 (Imiginis, 2005 as cited in Helms, O'Hea & Corso, 2008). Although women of all ages appear to experience similar symptoms of distress, younger women affected by breast cancer often present elevated levels of anger, and show greater concern about potentially leaving behind young children (Avis, Crawford, &

Manuel, 2004), demonstrating that the experiences of breast cancer diagnoses vary depending on intersections such as age (Cimprich, 1999).

Many studies have emphasized that the uncertainty during the wait for treatment and/or surgery is a monumental stressor (Fogarty & Cronin, 2008 as cited in Drageset et al., 2010). One of the factors underlying this sense of insecurity is a lack of information about breast cancer and the trajectory for treatment, as well as a limited understanding of available information (Gaudine et al., 2003; Saares & Suominen, 2005; Shaha et al., 2008 as cited in Drageset et al., 2010). Coming to terms with issues around mortality and acknowledging that breast cancer can potentially be fatal are other factors contributing towards heightened anxiety levels (Giske et al., 2009; Remmers et al., 2010 as cited in Drageset, 2010). Adjusting to, and accurately interpreting the situation often requires psychosocial support structures and counselling (Mehnert & Koch, 2008; Mishel, 1988 as cited in Drageset et al., 2010). And it is important to note that accumulating unresolved distress frequently informs longer-term mental health problems. This, in turn can lead to difficulties in adjustment, to depression, and to trauma as long as 20 years after the initial diagnosis has taken place (Lally, 2010).

Information and understanding various forms of breast cancer treatment is generally available. Nonetheless, American studies have shown that white women and women with a better standard of education are generally better informed than African-American women and women with less education (Chen, Diamant, Thind & Maley, 2008). Women who have access to the internet and/ or health pamphlets, or who communicate well with their doctors, appear to show a higher degree of knowledge. Conversely, statistics are difficult to collect on low-income women in remote areas who struggle to access doctors or clinics. It follows that they are burdened in a number of ways: fewer resources, possible illiteracy, causing lack of knowledge or misinformation, place them in an unenviable position (Chen, Diamant, Thind & Maley, 2008).

Adjustment processes are made possible by thought patterns and behaviours that make it easier to understand and incorporate a breast cancer diagnosis into a perception of the self. As such, initiatives aimed at women's understanding and accepting a diagnosis is of importance (Lally, 2010). Additionally, being able to trust and rely on health officials helps to decrease feelings of uncertainty (Mishel & Braden, 1988 as cited in Drageset et al., 2010). In light of this, setting a date for treatment to begin is seen as a crucial aspect in giving patients a sense of control and a sense that the healthcare system will 'protect' them (Drageset et al., 2010).

2.10) Illness Trajectory

According to Cimprich (1999), four phases make up the pre-treatment period of cancer patients. The pre-diagnostic juncture, involves the revealing of a physical complaint indicating a possible presence of cancer in the body. This subsequently calls for a diagnostic assessment, requiring a biopsy and verification of the presence of breast cancer. If a breast cancer diagnosis is confirmed, and the degree to which the body has been affected has been established, the third phase commences. This stage includes gaining information and guidance regarding decisions in terms of possible treatments and necessity for radiation treatment and adjuvant therapy after surgery. The final and fourth phase is committed to further medical assessment and planning towards either a lumpectomy or partial resection, or mastectomy, depending on the severity of the breast cancer (Cimprich, 1999). In most cases, these stages take place in quick succession. However, many patients are affected by substantial hurdles and are forced to endure longer waiting periods between these phases (Cimprich, 1999). This waiting period frequently determines client satisfaction of healthcare services to a large degree (DiTomasso & Willard, 1991 as cited in Fogarty & Cronin, 2007). The rapidity of healthcare services is often deemed to be a marker of quality of care (Eilers, 2004 as cited in Fogarty & Cronin, 2007). However, it has been put forward that waiting periods and waiting lists exist due to the fact that healthcare sectors often have limited resources. As a result, healthcare is rationed and prioritized (Fogarty & Cronin, 2007). Thus, members of higher socio-economic status are more likely to have access to better facilities and speedier services.

2.11) Conceptualizing Illness in Women's Bodies – Heterogeneous Experiences

Previously, cancer has been referred to and conceptualized as an acute disease (Tritter & Calnan, 2002 as cited in McCann et al., 2010). However, medical improvements have made it possible in recent years, to be diagnosed with cancer, and to be able to live longer with treatment. As a result, cancer is being reconceptualised as a chronic disease (Tritter & Calnan, 2002 as cited in McCann et al., 2010).

According to McCann et al. (2010), having a chronic illness causes disorder to an individual's 'normal' daily routines and can cause 'biographical disruption' (Bury, 1982 as cited in McCann et al., 2010), affecting how patients perceive themselves and/ or how they believe others to perceive them. Being diagnosed with cancer "immerses the patient into a

complex web of interrelated experiences” (McCann et al., 2010, p. 1974). Conceptualizing and dealing with cancer as a disruption to everyday life enables the exploration and understanding of cancer as situated in relation to the self. This disruption can lead to the perception of social isolation and/ or of being different, compounding in a sense of feeling a failure to fit in (McCann et al., 2010). With regard to breast cancer patients, the removal of one or of both breasts may make women feel that they are no longer able to fulfil hegemonic ideals such as being heterosexually desirable objects (Lorber, 1994). This shows that viewing cancer as a long-term illness, and understanding women breast cancer patients’ experiences within a larger framework of patriarchal, hegemonic social structures, is vital to enable researchers’ understanding of the necessity for adequate support structures for individuals battling with the disease (McCann et al., 2010).

Furthermore, there appears to be an assumption that the experiences around breast cancer, and other types of cancer as well as other life-threatening diseases have a lot in common. In addition, breast cancer patients are viewed as having gone through, or going through similar experiences and are thus perceived to be a homogeneous group of women (Arman & Rehnsfeldt, 2003).

2.12) Women Coping with Diagnoses

According to Lally (2010), a breast cancer diagnosis not only affects health and wellbeing but also impacts on women’s evaluation and perception of how they view themselves. This also influences women’s identification as a ‘breast cancer patient’ or a ‘cancer survivor’ or the rejection of such an identity. Research also shows that the kind of treatment undergone for breast cancer can have a significant impact on women’s perceptions of self. It has been suggested that chemotherapy is frequently linked to sexual dysfunction, and that undergoing a mastectomy often leads to problems in a woman’s body image (Avis, Crawford & Manuel, 2004). The perception of the self is challenged, depending on the ways in which family and friends respond to information about a breast cancer diagnosis as well as its impact on an individual’s previously held (and socially expected) multiple roles, including those in social, family and work spheres. Additionally, women sometimes try assigning significance to previous actions or behaviours in order to try and explain the cancer in their bodies. This often results in a threat to their sense of self. In light of this, acclimating to bodily as well as emotional and psychological changes can help to resolve these threats to self-integrity (Lally, 2010). Important to note at this point is that receiving a diagnosis for breast cancer brings

with it an entirely new environment filled with countless doctors, complicated terminology and new roles (Lally, 2010).

Studies suggest that coping mechanisms resorted to in response to a breast cancer diagnosis play an important role in overall successful management of the disease (Drageset, Lindstrom & Underlid, 2010) and can indicate how well patients will be able to adjust after having received treatment (Degner et al., 2003; Shou et al., 2005; Jadouille et al., 2006 as cited in Drageset, Lindstrom & Underlid, 2010). It must be noted that women are not a homogeneous group and therefore have different experiences and also varied ways of coping with these (Drageset, Lindstrom & Underlid, 2010). As such, individuals physically affected by cancer exhibit different coping techniques. These include active acceptance (Roussi et al. 2007, Stanton et al. 2002 as cited in Drageset, Lindstrom & Underlid, 2010), defensive coping (Stanton et al. 2002 as cited in Drageset, Lindstrom & Underlid, 2010), and avoidance-oriented approaches (Stanton et al. 2002, Hack & Degner 2004, Schou et al. 2004 as cited in Drageset, Lindstrom & Underlid, 2010).

The ways in which diagnoses are addressed can positively or negatively influence the entire illness and treatment trajectory as well as post-surgery outcomes (Drageset et al., 2010). Detecting breast cancer early and initiating a speedy treatment plan presents the best chance at long-term health and survival (McCann, Illingworth, Wengstroem, Hubbard & Kearney, 2010). Conversely, delays in treatment negatively influence prognosis and can worsen survival rates (Bickell et al., 2006; Blackman & Masi, 2006; Hershman et al., 2003, 2005 as cited in Rosenzweig et al., 2011). According to various studies, the types of support needed by women affected by breast cancer vary considerably, depending on: culture, type of treatment and the amount of time that has elapsed since diagnosis. These studies also note that women's needs frequently go unmet (Dickerson, Alqaissi, Underhill & Lally, 2011).

Some common findings have highlighted that social support is fundamental in women successfully coping with a cancer diagnosis. Social support is defined by Cohen (2004 as cited in Dickerson, Alqaissi, Underhill & Lally, 2011) as the provision of psychological, informational and emotional support by a woman's social network, with the intent of reducing and helping an individual to cope and to deal with stress.

Eriksson (1994; 1997 as cited in Arman & Rehnsfeldt, 2003) makes reference to patients potentially being able to turn to a 'development of suffering' with the help and encouragement of social support networks. This theory is based on the idea that individuals affected by cancer need to feel cared for, supported and understood by those around them. A cancer diagnosis is not limited to a person's physical experiences, but also impacts a person's soul and spirit. Minimizing these experiences to exclusively physical ones prevents women (and men) from being able to deal with existential and spiritual afflictions (Arman & Rehnsfeldt, 2003).

However, it often appears to be the case that family and friends themselves struggle with the knowledge of and acceptance of a friend's or a family member's diagnosis. And despite their best efforts to offer support, these challenges frequently translate into a lack of understanding and/ or failing to adequately meet the required needs of the individual affected by the cancer (Gorman, 2006 as cited in Dickerson, Alqaissi, Underhill & Lally, 2011). According to Figueiredo et al. (2004 as cited in Dickerson, Alqaissi, Underhill & Lally, 2011) these hurdles need to be overcome, as unsupportive communications and interactions can have a negative impact on patients' adjustment to their diagnoses.

Studies also highlight the importance of a supportive spouse or partner (Avis, Crawford & Manuel, 2004). It has been documented that already well-functioning relationships are often strengthened between a woman and her spouse or partner, when a breast cancer diagnosis occurs. Conversely, bad relationships (typically compounded by a low income or unemployment) frequently experience added strain by news of a breast cancer diagnosis and regularly end in separation (Avis, Crawford & Manuel, 2004).

2.13) Implications for this Research

In order to adequately aid individuals in developing coping skills, the onus is on doctors and on other carers to understand that there may be as many differences as there may be similarities in how women undergoing and waiting for breast cancer treatment deal with their situations.

Some of the core issues raised in this literature review have included a brief overview of how women's bodies and their health were, and sometimes still are, made invisible, and how women's involvement in their own treatment has been marginalized due to their 'second-

class' status and the paternalistic approach of the traditional medical model. In addition it has been highlighted that much of the literature on breast cancer has focused on quantitative methods to evaluate incidence and prevalence rates. It would also appear that there is a lack of qualitative research focusing on women's lived experiences, including women's illness anxieties, their uncertainties and their coping strategies throughout breast cancer treatment. Furthermore, it has been noted that breast cancer not only affects physical health, but also influences women's evaluations and perceptions of themselves and their femininity. It is argued that women's lived experiences of breast cancer and the treatment process are important in informing and developing adequate health initiatives and providing health programmes to patients and survivors. The importance of psychosocial support structures and counselling is emphasized.

This literature review strived to explore key areas of research and has helped to highlight some important arguments and emerging questions such as how the embodiment of disease impacts on dominant constructions and ideals of femininity, the need to discover women's experiences of the lengthy waiting periods between diagnosis and various treatments, as well as how this affects what it means to be a woman. Using a qualitative approach and a gendered lens, this research attempts to draw attention to previously overlooked experiences, taking power dynamics, race and class into account and focusing on the hurdles experienced by women throughout the breast cancer treatment process.

Chapter 3: Background

3.1 Cancer Association of South Africa (CANSA)

This research, apart from forming the topic of my honours thesis, is meant to contribute to the knowledge base of the Cancer Association of South Africa (CANSA). CANSA is a non-profit organization which funds cancer research but also promotes public awareness and education initiatives around known causes of cancer. It is also an organization which forms a type of watchdog role in terms of health policy in South Africa and it provides support structures to patients and family members affected by cancer.

CANSA also makes available interim care homes. These residences offer accommodation to patients who have had to travel far to access treatment, and provide lodgings for an average of six weeks. Transport and meals are also provided for patients, making their visits to and from hospitals and clinics, and their treatment processes more bearable (CANSA, 2009).

Additionally, psychosocial support is made available to cancer survivors and their families (CANSA, 2009). It is my hope that the research produced by this project will be beneficial to CANSA and the support structures it provides.

3.2 Personal Experience

“Feminism is as much about transforming what goes on in the minds and hearts of women and men as it is about realising rights and justice” (Pereira, 2002).

I strongly believe that it is important for me to be doing something important with my life, and something which is beneficial to others and not just to me, specifically in the area of social justice. I am hoping to achieve this by doing feminist research in an area that uses women’s lived experiences to inform breast cancer healthcare.

My reason for choosing to do research in the area of breast cancer is because my grandmother was diagnosed with it and struggled with cancer for years before she died. Apart from my grandmother, I have had countless family friends who have had to endure a breast cancer diagnosis and its treatment.

Using this backdrop, I feel that even though my body has not been affected by breast cancer, my person and my family have, and therefore this research is still quite a personal journey.

Chapter 4: Focus & Rationale

4.1 Breast Cancer Research and Feminist Studies – Taking Gender Seriously

Given the patriarchal structures of our society it is men's voices that are predominantly heard and women's voices that are silenced. On a topic which affects almost exclusively women's bodies, this research attempts to explore women's lived experiences and conceptualizations of breast cancer; experiences of breast cancer treatment, and the hurdles experienced during various stages of or between phases of treatment; as well as how these experiences influence perceptions around femininity and womanhood, essentially emphasizing that the personal is indeed political.

Using a feminist framework, the research attempts to highlight different ways of conceptualizing women's concerns, made invisible by subtle processes of domination (Pereira, 2002). As such, this research seeks to discover "new conceptualizations [and] wider realities" of women's experiences with breast cancer (Pereira, 2002, p. 2). As such, a main research focus and two sub-questions were developed.

4.2 Main Research focus

What are survivors' experiences of breast cancer treatment?

4.3 Sub-Questions

- 1) How do women experience the waiting period between diagnosis, surgery and radiation therapy?
- 2) How do breast cancer diagnoses and struggles with breast cancer shape perceptions of femininity and womanhood?

Chapter 5: Research Methodology

5.1 My Approach

My approach to research is one which takes gender seriously. I like to think that my research is grounded in a liberal feminist framework, but that my approach is also influenced by a socialist feminist agenda. I believe that there is great importance in taking both public spaces and private spheres into account and that “knowledge production can never be neutral... [that] we need to uphold the principle that gender is a fundamental axis of division and power in all social processes and relationships (Pereira, 2002, p. 2).

5.2 Feminist Insights into a Methodological Approach

Three readings in particular, by feminist writers Bhavnani (1994), Palmary (2006) and Patai (1991), have hugely aided my development in doing research while taking gender seriously. The themes covered by these authors, namely feminist objectivity, reflexivity and ethical research, were drawn on throughout my research process and my analysis.

Some of the key points made by these writers and ones which I have taken very seriously include Bhavnani’s (1994) insistence that women do not simply make up one homogeneous group of people, but that each woman lives a different experience. As such, it is vital to take women’s varied intersections of race, class and background into account. Recognizing, acknowledging and addressing differences in experiences amongst interviewees, is essential to feminist research.

Furthermore, Bhavnani (1994) maintains that feminist objectivity can be achieved through accountability and positionality. This implies that the ways in which an individual is represented within research should not emphasize dominant perceptions about that person as a victim; and that I need to be aware of my presence as a young, white, female student from a privileged background, how this may influence the connection made between myself and my research participants, as well as how this may affect the knowledge produced during the interview (Bhavnani, 1994). Questioning what knowledge truly is, and how it comes into existence and by whom, are important considerations to make during the process of feminist research (Okazawa-Rey, 2009). Furthermore, it is vital to take issues of race and class into account.

Palmary (2006) emphasizes this point further by highlighting that my presence impacts on the knowledge that is brought to the foreground by patients. As such, the research findings produced here do not represent a static and pure experience of what it means to be diagnosed with breast cancer and waiting for treatment, but rather reveals a co-production of information and knowledge, produced in collaboration with my research participants.

Palmary (2006), also highlights the importance of acknowledging women as individuals and as having made varied and individual experiences and not to represent my research participants as a homogeneous group within my research. Furthermore, my own experiences are clearly very different from the experiences made by my participants. In light of this, I needed to be cognizant of my own privileges and the fact that I have not personally experienced what it is like to be diagnosed with cancer and thus do not form part of their 'group'. Being completely aware and sensitive to these differences was and continues to be vital, as it informed the kinds of questions I asked my research participants, influenced the ways in which I asked these questions during the interview and impacted on the way I interpreted their responses. Palmary's reading (2006) also emphasizes that the knowledge obtained throughout interviews would be situated and from a certain perspective. Finally (and of great importance to this research), I have been very careful about the ways in which I have represented my research participants in this write-up, as I am hoping that this research will be a positive contribution in advocating for better treatment policies.

Patai (1991) emphasizes that the more economic / social / political differences there are between the researcher and researched, the more risky the research process becomes and the more ethical considerations are necessary. In addition, Patai (1991) highlights that individuals need to be recognized and acknowledged for their particular life events.

Furthermore, doing feminist research essentially includes the consideration of social transformation (Pereira, 2002). My research advocates for social transformation by questioning the construction of femininity and taking into account the importance of breasts in achieving this social construct as well as advocating for improved healthcare amongst primarily low-income women in the South African context.

5.3 Broad Choice of Methodology

For the purpose of this research, a descriptive, qualitative research method was used. Due to the fact that this thesis is an attempt at better understanding the experiences of breast cancer

patients, it was decided to employ the method of an in-depth, semi-structured interview with open-ended questions in order to fully explore complex topics. A qualitative stance takes culture, history and society into account so as to better understand the experiences and actions of participants (Maracek, 2003). Furthermore, a qualitative stance allows for an individual's subjective experiences to be taken into account (Terre Blanche, Kelly & Durrheim, 2006) as well as demonstrating that participants are active agents in the way that they understand their own experiences (Maracek, 2003). In addition, this form of methodology allows for the variability in experiences within and between groups to be highlighted (Avis, Crawford & Manuel, 2004).

This research also made use of participative methodology, as the project was predefined by CANSA and UCTs Knowledge Co-op. This means, that I have been working with others who have set the terms of this research. In light of these terms and conditions, I set out to explore women's lived experiences and conceptualizations of breast cancer, to unpack women's meanings of waiting for months for treatment as well as to investigate how these experiences shape constructions of femininity. It is my hope to contribute to CANSA's knowledge base and that this research can aid in the process of advocating for better treatment policies.

5.4 Description of Research Methods:

5.4.1 Data Collection – Recruitment: Convenience Sampling

Initial contact with CANSA was made through UCTs Knowledge Co-op and a meeting between Barbara Schmid of the Knowledge Co-op, Dorothy Du Plooy from CANSA, Adelene Africa of the African Gender Institute at UCT (and supervisor of this thesis) and myself, to discuss CANSA's research requirements and needs, as well as to consider what I hoped to explore through my honours research. Once we had agreed on some ideas and the best way for this research to move forward, Dorothy Du Plooy provided me with two contact numbers for CANSA care homes in Athlone and Tygerberg in Cape Town, South Africa. These homes are often also referred to as a home-from-home and provide residence for cancer patients needing accommodation in order to be closer to cancer treatment facilities. Women cancer patients who had undergone breast cancer surgery and were awaiting further treatment or who were dealing with breast cancer and radiation therapy and staying at one of CANSA's care homes, were the patients I was interested in interviewing (CANSA, 2009).

A visit to both homes was scheduled for the 25th of July 2012. Accompanied by Denise Da Rocha from CANSA, Barbara Schmid and I were introduced to Michelle May and Mandy Engelbrecht who perform the role of house-mothers at Eikehof and Tygerberg respectively. Here, I first introduced my research, and described some of the areas and questions I was interested in. I also handed out a short written summary of the research proposal with an invitation to patients to participate.

At Eikehof, I was given a small tour of the home, but was not immediately introduced to any patients. Given the emotional and vulnerable state of some of the breast cancer patients, Michelle May and I agreed that it would be best for her to speak with them first about my project and then let me know how many patients were interested in taking part in the research process.

At Tygerberg, after discussing my research with Mandy Engelbrecht, I was quickly introduced to three breast cancer patients, to whom I also explained what my research was about and what I hoped to achieve with my thesis. All three patients at Tygerberg were eager to take part in the research process and interview schedules were immediately made for the following morning of the 26th of July 2012. This was largely due to the fact that two of the three patients at Tygerberg were nearing the end of their stay.

As such, participants were recruited from two CANSA home-from-home locations in the Western Cape. Due to the fact that there were very few women with breast cancer diagnoses residing at said homes during my research time-frame, participants were chosen on the basis of their availability and willingness to take part in the study. In light of this, I got into contact with my research participants through a process known as convenience sampling (Terre Blanche, Kelly & Durrheim, 2006).

5.4.2 Research Participants – Criteria

The sample for this research consisted of five primarily Afrikaans speaking South African women. All research participants were in treatment for breast cancer at the time of interviews. Apart from one patient, who had only recently been diagnosed, all research participants had already undergone surgery, were at various stages in the treatment process and had already or were in the process of enduring a lengthy waiting period between surgery, chemotherapy and/ or radiation therapy. My selection criteria did not exclude anyone based on race, socio-economic status, age or stage of treatment. However, all participants were women of colour

between the ages of 30 and 60, of low socio-economic status and had travelled from areas like Worcester, Ceres, Clanwilliam, Saldanha, and Springbok to gain access to treatment.

5.4.3 Data Collection - Semi-structured Interviews

Taking the afore-mentioned elements of feminist research and methodological frameworks into account, I have used a qualitative approach to conduct in-depth, semi-structured interviews. The use of semi-structured interviews allowed for similar themes to be explored with each participant, but within a more flexible framework (Dearnley, 2005). Using this method allowed participants to share their experiences with me and provided a space in which I was able to ask additional questions that arose during and throughout their telling of experiences. As a result, this qualitative, semi-structured approach permitted an exploration of occurrences and experiences, providing depth, strength and quality to the data being generated (Dearnley, 2005). The semi-structured interview format also allowed for a better and easier flow in conversation than a more structured format or a different methodological framework such as quantitative research would have been able to provide, and thus enabled reflection on experiences, providing a better setting to make participants feel more comfortable with sharing their stories (Dearnley, 2005). Quantitative methods tend to encourage the generation of superficial data and are collected through a somewhat exploitative relationship between the research participants and the researcher (during which participants are not acknowledged for their contributions and their roles as co-producers of the research). These also frequently marginalize or exclude female subjects in research and are often not used or focused towards social change (Oakley, 2002). Quantitative methods would also only be able to research isolated sections of women's experiences in this sort of research. A qualitative approach on the other hand allowed me to explore these experiences in a more holistic manner (Drageset et al., 2010).

As time was a key factor for both patients and researcher, each interview was scheduled to take between 30 minutes and an hour (Dearnley, 2005). However, due to the fact that some participants felt more comfortable with sharing their experiences than others, the actual interviews ranged from 35 – 90 minutes. Interviews took place in July of 2012 in a quiet and private setting at each of the care homes and all but one session were conducted in Afrikaans. Interviews were audio-recorded and transcribed, using pseudonyms in order to maintain confidentiality. Interview sessions began with my asking patients how they were doing and whether they were willing to relate their thoughts and experiences around their diagnosis and

battles with breast cancer. Research participants were allowed to speak freely with no interruptions. Only when elaborations were required did I revert to probing or additional questions outlined in Appendix A. The aims and themes of questions asked were structured around women's experiences of the waiting period between surgery and radiation therapy, their experiences of support, and how women conceptualized and perceived their breast cancer diagnoses, as well as how their struggles and experiences influenced their perceptions of femininity.

5.5 Method of Analysis

Interviews were recorded and transcribed. Narratives were explored using a qualitative analytic method known as thematic analysis to identify, analyse and explore themes within the generated data. This method helped to organize, describe and interpret complex research findings (Braun & Clarke, 2006). This type of analysis involves sifting through and across data to discover recurring themes. Thematic analysis allows for themes to be determined in several ways. Themes could detail patients' experiences, and meanings and truths of these experiences (essentialist method); or themes could detail the ways in which these occurrences are influenced and created through social discourse (constructionist method); alternatively, themes could be drawn to represent the ways in which participants understand their experiences (contextualist method) (Braun & Clarke, 2006). The methods used and the themes created depend primarily on the information that arises during the research process and the ways in which this relates to the research question(s). Braun and Clarke (2006) suggest six steps in conducting a thematic analysis: these steps include the transcribing of interviews and familiarising oneself with the data through repeated reading of the data; the establishment of codes; discovering themes by considering how several codes could potentially come together to create an overarching theme; reviewing these themes; identifying, refining and naming final themes as well as sub-themes; and finally producing a written analysis (Braun & Clarke, 2006).

5.6 Conducting Ethical Research

Patai (1991) underlines the fact that research between two parties in which one party comes from a more privileged background can quickly become a risky situation. The worry lies in that one person or one 'group' of people may be exploited to the advantage of another under the pretence of doing valuable research. As such, there are many ethical considerations that

need to be taken seriously. In order to avoid any ethical dilemmas, two important processes took place:

a) Vetting Process

After submitting a final thesis proposal to the African Gender Institute at the University of Cape Town, and being given ethical clearance by the gender department, the proposal was submitted to and approved by the University's Knowledge Co-op and Dorothy Du Plooy from CANSA. A Memorandum of Understanding (MoU) was drafted by Barbara Schmid, and signed by all parties. A copy of the MoU has been attached as Appendix B.

b) Informed Consent

At the very beginning of each interview, research participants were again informed that I was conducting research as an honours student at the University of Cape Town and I briefly explained the themes to be explored throughout the interview. I also clarified that my research was for the CANSA organization, and that I had been able to gain access to them as potential research participants through CANSA. I and my research participant talked about the study procedure, including an estimated duration of the interview. I explained that there were no known risks to be incurred by participating, but that participation was completely voluntary and that deciding not to participate or refusing to answer specific questions would not impact negatively on research participants' relationship with the clinic, hospital or home in any way. I added that potential benefits included generating important information that could be useful to inform the development of necessary emotional support and to advocate for additional capacity for treatment. I explained that all personal information would be kept strictly confidential. I asked for permission to record each interview, which research participants granted me. After these issues had been discussed, understood and accepted, and only once the consent forms (attached as Appendix C) had been read and signed, did the interview officially begin.

Only I and my supervisor, Dr Adelene Africa, had access to the raw data produced during the research period. This included transcripts and recordings of the interviews. In addition, I completed all transcriptions on my own, in order to become completely immersed in the data and to negate any issues of confidentiality that could arise by using outsiders to help in the transcription process. Furthermore, I will be offering my participants access to my final

report as well as to their transcribed interview in order to include them and acknowledge them as co-producers in this research process (Dearnley, 2005).

5.7 Positionality

My positionality as a young, white, university student from a privileged background is most decidedly different from my research participants' experiences. Being South African citizens, and being categorized as women gave us common ground in terms of unspoken and invisible patterns and influences of being gendered and being expected to fulfil feminine and womanly roles in our communities and society. However, the differences in our backgrounds, our class and our age as well as our life experiences, placed each of us at very different levels of knowing and understanding our bodies and our worlds. This no doubt influenced the type of answers and information that my participants were willing to share with me. As such, it was evident that the micro-politics of this research included race, age, class, personal backgrounds and language.

Though remaining unspoken, I believe that power hierarchies were a constant throughout the interviews. On the one hand, while I cannot claim to know how I was perceived by my research participants, introducing myself as 'a researcher' appeared to give some participants the impression that I was already some sort of expert on breast cancer. This became increasingly clear when patients used medical terminology and seemed to expect me to know exactly what they were speaking about, or when they asked me questions about their health and their treatment. While certain perceptions may have placed us at different levels of a power hierarchy, real knowledge and actual experiences of breast cancer also put my participants in a position of expertise and power. It became increasingly clear, that my experiences with breast cancer outside of my own body placed me as an 'foreigner' in comparison to my research participants who had made experiences with breast cancer on their own bodies and were therefore experts on this.

Although there were great differences in age, the willingness and openness and potentially the need to verbalize their experiences and to tell an outsider their stories made it unexpectedly easy to connect with my research participants. However, the language barrier prevented this communication from being completely flawless and conversational. The more interviews I conducted, the more comfortable I began to feel about asking questions in Afrikaans, and I am sure that this played a role in how comfortable my interviewees felt and

this would have impacted on the type of information they provided. Overall, while it was difficult, the process was not an unpleasant or uncomfortable experience.

5.8 Limitations and Challenges

The fact that my first language is English and my research participants' first language is primarily Afrikaans, posed a substantial challenge to conducting interviews. As a result, initial interviews were far less conversational than I would have liked and I tended to stick to prepared questions rather than probing in Afrikaans. This, however, improved as I conducted more interviews and felt increasingly comfortable with my task of interviewing in Afrikaans. Nonetheless, this language barrier further impacted on later stages of my research, as it was very time consuming for me to transcribe each interview.

Additional challenges included the choice of themes. I worried about the fact that I was not properly doing justice by my participants and the wealth of information they had provided me with, by limiting my analysis to several areas rather than discussing everything we had spoken about.

In hindsight, I believe that it would have been good to organize a focus group in addition to the individual interviews. This may have been beneficial in that participants would have felt more comfortable about speaking of common experiences and would have aided my research as well as potentially providing patients with a supportive setting to talk about their experiences.

Chapter 6: Analysis and Findings

To investigate the data obtained from the five semi-structured interviews, a thematic analysis was used (Braun & Clarke, 2006). A number of related themes describe women's experiences of breast cancer. These themes range from the initial stage of diagnosis, to experiences throughout treatment, to sources of support, and the meanings and perceptions of what it means to be a woman, as well as what it means to have cancer. These themes also illustrate patients' needs and unanswered questions. One overarching linking pattern demonstrates a shared experience by all five participants, namely, that of women forming the backbone within their families, providing emotional and financial support, regardless of their own health needs. Each theme is introduced and briefly described in English, with some examples of transcribed data to support this interpretation. These quotes are presented here primarily in Afrikaans as this was the language used to conduct interviews. The analysis of the research findings places great emphasis on how various experiences, by five breast cancer patients, are gendered.

Participants ranged between 30 and 60 years of age and varied in phases of treatment. While one woman had only recently been diagnosed with breast cancer, others were busy with chemotherapy or radiation therapy, while some had completed all treatment and were preparing to return home. All participants were either married or had been widowed, and all women had minor dependants. In addition, every one of these five women had travelled from distant and outlying areas such as Worcester, Ceres, Clanwilliam, Saldanha and Springbok and were residing at one of CANSA's care homes in either Tygerberg or Athlone.

6.1 Finding Cancer in the Body – First Experiences of Breast Cancer

Bearing in mind that all five research participants were at various treatment stages, a prominent theme throughout all of the interviews was each woman's first experience of finding a lump in her breast and the shock and disbelief women felt when their suspicions were confirmed by a doctor's breast cancer diagnosis. Some women were more expressive about their initial feelings, while others responded in a far more conservative, possibly shell shocked, manner.

P2) "Ek het dit nooit geglo! Dan sê sy dit vir my weer. Jy het cancer, jy het kanker en jou bors moet af... ooooooooooh!!! Ek het só gehuil! Ek het so gehuil. Ek het uitgegaan, die deur toegegooi en só gehuil!"

P5) "Ek voel net, um... ek gaan aan."

This may have been due to the fact that most patients had had time to reflect on these experiences while one patient had only recently received her diagnosis at the time of the interview, and seemed to be in a state of astonished paralysis about the whole situation.

In response to my question about this first experience, patients were able to remember in great detail things like the month and even the exact date on which they first felt the lump, signifying how incisive this experience is – a watershed moment in their lives:

P1) “I had felt it [gestures to breast] on the 17th of May... I felt a lump. So I was, I was, I was worried. I didn't sleep that night... And so the next day I went to the doctor.”

P3) “In September 2010: Toe voel ek hier is ‘n knoppie... All of a sudden, toe lê ek op ‘n Sondagmiddag op my rug.... September... voel ek watsie knoppie is dié in my bors?! En ek maak seker, ek lê so op my rug, en ek soek my bolyf op en ek maak seker – nee, maar dit IS ‘n knoppie! En ek gaan die Maandag kliniek toe.”

One patient's response also seemed to indicate either a lack of knowledge with regard to picking up on symptoms, or denial which ultimately resulted in the cancer spreading through her entire breast:

P4) “Toe kom die dokter na my toe, toe sê hy vir my, ja, die hele bors het kanker in gehad... daar was nie ‘n sentimeter wat nie kanker had nie.”

6.2 Breast Cancer – the Patient's Perspective of Treatment and Waiting Periods

Patients also made various experiences at different stages throughout their treatment processes. One of the most important topics that arose dealt with how each woman perceived her breast cancer experience. This was vital to understanding the treatment process through these women's perspectives.

One breast cancer patient described how, after receiving her diagnosis, she was asked by her doctor to book herself into the hospital. However, on arriving there, the hospital staff refused to admit her on account of a previous payment for her husband's operation not having been settled by their medical aid:

P1) “... when I went there for the pre-admission, I didn't know that the account hadn't been paid... of my husband's... and that was a few years back, 2007's account, that wasn't paid by the medical aid. So they didn't want to admit me. They didn't want to admit me...”

This resulted in the patient having to seek treatment elsewhere, which is what ultimately led her to Tygerberg Hospital, where she had to endure another huge disappointment when

hospital staff eventually told her that instead of removing only a portion of her breast, as they had initially planned, they were going to have to remove the whole breast.

P1) "...then they told me they couldn't save my breast."

This woman found the waiting period between diagnosis and surgery particularly long and expressed that her cancer grew far too much during this time, which no doubt led to her whole breast needing to be removed. She says:

P1) "I think that they could have hastened the process, because you know, you keep on worrying and worrying and worrying... when is this thing going to end. And you know sometimes, last year here in November/ December, you could see that this thing was growing inside of you. And they said at first: it was small! And then afterwards it was the size of a tennis ball! So, uh, that was quite worrying!"

Another patient also expressed her disappointment and shock at the fact that her whole breast was removed. She too had been promised that only a small section needed to be cut out.

P3) "In die eerste plek was ek nie baie happy nie, hulle het gesê hulle sal die klomp kan verwyder, maar agterna hoor ek, nee, maar hulle gaan die hele bors verwyder... en toe is ek nou 'n bietjie.... in, in, in, in... skok."

The last interview, conducted with a woman who had only recently been diagnosed, further emphasized the common concern about losing a whole breast. She explained to me that hospital staff had informed her that they would only need to cut out a particular section of her breast. And that they would surgically make her other breast smaller, too, in order to preserve a feminine body which appears in proportion.

Another patient also articulated great concern about the speed at which her cancer grew:

P2) "dis kwaai want die ding het gegroei. Dit was eers 4cm. Toe ek hier kom vir die chemo, was dit 10. Dis so 'n groot klomp gewees."

Others experienced this period slightly differently. One woman described that she thought that there had simply not been a place for her in the operation theatre and that there had been a delay in schedule due to burst waterpipes. My fourth research participant did not experience too much of a wait at all. She maintained that her health was already at such a critical stage, and that the cancer was growing so fast that doctors had to remove the breast immediately instead of sending her for chemo in an attempt to reduce the cancer.

P4) "Hulle het gou gespeel... hy't vinnig, vinnig... hoe kan ek sê... die kanker was 'n agressiewe kanker... soos die dokter vir my sê... hy groei te vinnig. Toe het die ding al hoe groter, en groter, en groter geword..."

Voor hulle die operasie gedoen het, toe was hy hierdie, hierdie hele gedeelte was vol. Dis hoekom hulle my nie gestuur het vir, vir, vir Chemo of sulke goed nie. Dis hoekom hulle nou die bors sommer direk verwyder.”

However, while surgery occurred relatively quickly for this woman, setting up an appointment with her doctor to discuss her radiation therapy seemed very complicated and frustrating. At the time of this interview, she had been waiting almost three weeks to see him. As a result of this, and due to the fact that nobody was answering her questions, she was feeling completely out of control. And this was merely adding to the frustration that came with her diagnosis.

P4) “Nou ek word net gestuur, ek word net gestuur hier in ‘n leeuhoek in, dit is hoekom ek so huil, aanmekeer huil, want ek weet nie wat gaan aan nie.” (link this to paternalistic medicine)

She felt so discouraged about the fact that her doctor had not explained to her why she was undergoing radiation therapy, that she confessed she would rather cut her treatment short, pack her things and go back home to her husband. What more proof does one need as to where the most important/ core support structures are represented? How much stress does this feeling of being trapped cause, and how counter-productive is this in view of the disease?

P4) “Ek raak so beneuk, nê, ek voel ek kan iets nie oorkom want ek weet nie hoekom is ek hier nie. Hoekom moet ek hiernatoe kom.”

Treatment stages held various hurdles in store for these women. One patient described how her doctor removed her breast in such a way that there was some skin left over which could later potentially be used for reconstructive surgery. However, she explained that this section of skin became infected and that she got incredibly ill as a result.

P2) “Die dokter het vir my ‘n sort cap gesny sodat daar teminste ‘n vel is om oor te sit. Maar daai vel het gevrot. Toe moet ek weer na die hospital kom omdat dit septies geraak het. Ooh, ek was dan siek! Dit was so uitgedra, dat ek begin dink het die cancer is nog steeds in die bors, die cancer was nie reg uitgesny nie.”

In addition, she was expected to wash and take care of her wounds without much help from surrounding hospitals, clinics or nurses. She explained that her nearest clinic would not help her with cloths and saltwater washes and that she was forced to do this in her home and on her own. However, she eventually had to be readmitted at Tygerberg due to an infection and appeared to have been greatly shocked by her doctor’s comment that such a bad infection could lead to death.

P2) “Ek het baie moeilikheid gekry... Hy het gesê ek moet soutwater bruik om dit skoon te maak. En die kliniek het gese ek is ‘n Tygerberg pasient, en daar is geen lappies en sout in die kliniek vir my om my te was. Ek moet self by die huis gaan was. Ek het swaar gehad! Ek het selfs die soutwater daarop gesit, die soutwater met die lappie, ek moet dit self gedoen het... niemand het my gehelp nie. Self... toe sê ek vir ‘n vrou ek sal nou baie siek raak... toe gaan ek na my eie hospitaal, toe sê ek dokter kyk net my bors, ek is sooo siek. Toe sê hy, nee, ek moet hier bly. En ek vra dokter: kan ek hiervan sterf, en hy sê NATUURLIK! Jy kan daarvan doodgaan.”

6.3 Sources of Support

Patients mentioned several key areas and people as vital to their support systems. These included family, hospital staff, as well as other patients, and CANSA. Most of them also relied greatly on faith.

6.3.1) Family

Two out of the five research participants emphasized that their families, particularly their husbands and their children, had been vital in encouraging and motivating them and had been critical to them maintaining a positive outlook. This became increasingly evident throughout both interviews. One of these two patients spoke of her husband as having gone through all the cancer stages with her and that it was only now, during her stay in Athlone for radiation therapy, that they were forced to be apart for a while. This thought seemed to trigger deep sadness and she began to cry, while telling me that she missed him every single day and that she had to stay at Eikehof for a further five weeks. Communication with children also seemed to be very important and contact was maintained via skype and/ or sms. However, one woman mentioned that she could stay in contact via sms only while residing at Eikehof due to the fact that there was no access to skype.

Apart from husbands and children, one patient stated that she only felt comfortable speaking to her older sister and not her younger sister about her cancer experience because only her older sister was a cancer survivor as well. This patient felt that she could not speak to her younger sister due to the fact that the latter had not experienced having cancer.

The other three research participants did not perceive their families to be very supportive. In fact, two women spoke a lot about how abusive their partners were towards them, both before and after their breast cancer diagnosis.

P1) “I don’t have a very happy marriage... I would say that... all the abuse... I think... in the long run, it made me a very strong woman, I think. Because, you know what? The cancer was diagnosed last year in

May... and until this day, he has never asked me 'where are you going today' ... and he sees me getting into the car and going... But he never asks me 'where are you going today?' uhm... or 'how are you?' 'what is your diagnosis', 'what does the doctor say?' ... And I must say it hurt me very very deeply, you know. ”

P2) “wat vir my baie hartseer was... toe ek cancer gekry het...dat my man vir my gelos het. Die dag ek vir hom gesê het ek het cancer, toe vloek hy vir my... hy's kwaad vir my. En ek verstaan nou nie. Want die dokters het gesê ek moet vir my man en vir die kinders vertel. En die kinders het nog gehuil en so.. maar hy was net kwaad. En net voor ek die operasie gekry het... Toe gaan hy werk, toe kom hy nooit weer huis toe... En ek het hom so nodig gehad.”

My third research participant also highlighted that she had learnt that many people, whom she had considered as close friends, were not as supportive as she had hoped they would be.

6.3.2) Hospital Staff

Participants' responses to questions around hospitals and hospital staff varied considerably. The research participant who had been diagnosed most recently spoke about the fact that she was not familiar with Groote Schuur Hospital and that she did not really feel comfortable with the thought of undergoing the operation there, but that she did not want to offend her doctor by telling her so.

P5) “Maar, ek... ek voel dan nou dat my dokter mos dan sal sleg voel, want ek ken haar, en ek hou van die dokter wat my nou gesien het. Ek hou van haar gesig, ek hou van haar. Onmiddelik het ek van haar gehou. Dis hoekom ek toe nou nie wil vir haar in die gesig vat en vir haar sê sy moet nie die operasie op my doen nie.”

Another patient being treated at Groote Schuur emphasized the fact that the doctors and nurses were friendly, helpful and approachable. She recalled how she would occasionally get incredibly nauseous and that doctors and nurses helped to keep her morale high by making jokes and being around when she needed them. However, she disapproved of the length of time it generally took to set up an appointment with a doctor and complained that even when speaking with her doctor during a consultation she was not always confident that he was being entirely truthful towards her and often felt as though he might be keeping information from her. This ultimately gave her a feeling of being out of control and not as involved in her treatment process as she would have liked to have been.

One of my other interviewees also had a negative experience before being assisted by CANSA and Tygerberg Hospital. The following quote serves to highlight how, after

receiving her diagnosis, she attempted to book herself into a hospital in Worcester and how this had left her feeling completely dejected:

P1) “I phoned the receptionist at the doctor’s and I asked her to book for me at a state hospital there in Worcester. And she booked me for the 15th... the 15th and then all of a sudden, she phoned me again and she said ok, the doctor won’t be able to operate on me because he’s going on holiday... And he went on holiday that June, and then I felt – I’d been left. Left in the lurch... I felt the surgeon didn’t have the ‘menslikheid... ek het gevoel’ all he cares about is money. He doesn’t care about... Me.”

6.3.3) Other Cancer Patients

All but one of my research participants experienced the companionship and close proximity of other cancer patients in their respective care-homes as important and supportive. They frequently described this contact as “wonderful” and felt they were able to form valuable bonds with one another, grounded in a common understanding of what the other was going through. This encouraged women to keep a positive outlook and helped them see and learn how others in their position were dealing with the diagnosis and the treatment.

P2) “... dit was goed om hier te bly want almal praat een ding. Hy het cancer, sy het cancer, al die mense praat een story met mekaar.”

P1) “These people that I have been in contact with...and you know the one thing good about having cancer is the many, many contacts that you have... and the support system within the patients itself. And the feeling that you have when you come across a patient that you know have had treatment here at Tygerberg – you feel like it’s a brother or a sister that you have.”

Experiences included realizations that it did not matter whether one worked on a farm or in other people’s homes, or whether one was wealthy or poor, but that cancer could present itself in anyone’s body, regardless of race, class or gender.

P1) “If you have cancer, we all are equal. It’s just a fact. You have to go through the same experiences... maybe not the same treatment, but the same type of experience. And you know what I experienced as well? White and brown and black people alike get cancer. And it doesn’t matter whether you are white, yellow, black or blue. You are still human and you are still going through the same difficulties”

However, one lady did not seem to agree with the perspective that other patients could potentially act as a support network. She explained to me that she does not speak to other men and women at Eikehof about their experiences, her reason being that most patients had

been diagnosed with various and different kinds of cancer and that they were all therefore having different experiences, were on different, if vaguely similar, paths that did not in her view, dovetail.

P4) “Almal het verskillende kankers wat hier is.”

This woman was choosing not to communicate too much with other patients because she had created a negative association with their being at Eikehof. It became apparent that she was distancing herself from the other patients in order to separate herself from her diagnosis in an attempt at warding off potential consequences or results of the cancer. These feelings were expressed when asked whether she was still in contact with any of the patients with whom she had started her treatment at Somerset Hospital.

P4) “Nee ek het glad nie kontak met die ander pasiënte nie... want hulle sit vir my waar ek nie wil wees nie.”

And, although she seemed rather adamant about how she wanted to go about her situation, she appeared to be the least emotionally stable and least positive about her diagnosis and treatment out of all five participants. Her case signifies how lonely the emotional path can be in the face of this disease, how individual the battle, and how varied the process of dealing with it.

6.3.4) *CANSA*

Apart from feeling homesick and missing their families, research participants were very happy with the services they experienced through CANSA. These five women expressed their appreciation towards staff and volunteers, saying that these had helped keep a positive attitude by providing reading material and information on breast cancer as well as a contact number which could be used at any time to talk about their experiences, thoughts, questions and concerns. Being able to stay in a comfortable, safe, homely and convenient environment, away from the everyday responsibilities as wives and mothers also seemed to have been incredibly beneficial to their treatment process, as it alleviated much stress.

P5) “..Ek meen, ek het mos nou kinders wat ek aan dink, maar die verlanse was daarem maar nie so groot nie, want ek het gevoel ek is by die huis gewees... so lekker het ek gebly.”

Furthermore, the privacy and the calm environment provided by care homes offered women the choice of either chatting to fellow patients, staff and volunteers, or to take some time for themselves. One research participant, who seemed less willing to communicate with or form

relationships with the patients around her commented on this, saying that some days she feels that she needs to be on her own to cry. She appeared to be communicating that this could be as therapeutic as potentially talking about one's feelings.

P4) "Somtyds... ek kry, ek kry, ek kry... dan voel ek, ek wil alleen wees. En dan gaan ek in my kamer en ek huil my uit en dan voel ek beter, dan kom ek uit."

Two of the five participants even mentioned wanting to register with CANSA after moving back home, in order to volunteer and be able to help others in the same situation by talking to patients and providing information. One of these ladies emphasized the need to pass on her knowledge about breast cancer to her community, insisting that they did not know enough about being able to detect breast cancer at an early stage. She put her case in a very well thought-through and eloquent way which leads one to believe that her experience could, indeed, be harnessed to counsel others in future.

6.3.5) *Faith*

A deep-seated faith and trust in God was a prominent coping mechanism in four out of five interviewed patients. According to research participants, knowing that they had God in their lives was vital to their coping with their diagnosis and cancer treatments.

P1) "You have to have faith that you are going to cope with this."

Speaking to priests and asking for prayer as well as praying a lot themselves enabled women to feel calmer about their situation and gave them a sense of conviction that if God had brought them this far, He would help them get through each of the stages they were facing.

P1) "I went to him [a priest] and I asked him to pray for me. And I said he must now tell me what does the Lord say. Is it cancer or not. And so he prayed for me and he said it is cancer and then I asked him now you must ask the Lord what I must do. And when he opened his eyes, he said that the Lord wanted me to go through all the stages. And I did. Because I thought I must believe what the Lord said. That is the main reason why I am having chemotherapy."

P5) "Ek vra die Hemelse Meester om my nog... hy't my tot sovêr gedra... om my nóg krag te gee..."

In one patient's case, a lack of supportive family or friends was replaced by her steadfast faith that God would see her through this process.

P3) “The Lord is more than enough your support... I think by myself: it’s ok, because I know for myself that everybody’s going to disappoint you, but not God.”

6.4 Meanings and Perceptions of Being Woman

6.4.1) Abuse

Questions about what it meant to be a woman and how the breast cancer diagnosis had impacted on this were met with various responses. However, most striking were the comments made by two interviewees who shared a lot about their experiences with abusive husbands, and explained how this had shaped their perceptions of who they are as women.

P1) “And you know what that does to a woman? It makes you very hard. ‘Dis amper as of jou gevoelens afgestort word’.”

One woman explained how she suffered countless physical attacks at the hands of her partner, and that she initially thought that the breast cancer had been as a result of a kick to her breast. However, she maintained that having to go through this cancer experience had made her a stronger woman and she described how she would have previously cried about her husband’s continuous absence and would have felt worthless, but that she now felt stronger and able to confront him about his behaviour.

P2) “Ek voel sterker... As my man by die huis was, was ek sooo bly... ek huil, ek sê: moenie vir my los nie... ek weet nie hoekom jy so lelik is met my nie... hoekom raas ons so... maar die keer... nee. Ek voel, ek is nie meer lief vir hom nie...”

However, she also appeared to feel that her husband was an important person and potential ‘role model’ in the lives of her children and emphasized the value in letting him stay in her home for their sake. She also made a comment about him being the head of the household, despite the fact that she was the sole breadwinner for their home.

P2) “Ek is baie sterker... ek is nie bang hy sal nou weer weggaan nie. Ek worry nie. Hy’s ‘n groot mens, ‘n groot man.. Maar dis nog steeds my kinders se pa... en hulle moet hom respek. En hulle weet dit. Dat hy die man van die huis is.”

6.4.2) Education

Education appeared to be quite an important theme in the research participants' lives, both in terms of their own education and how this had been vital to their current level of well-being and status as women, as well as the value they placed on being able to provide the funds and emotional support to ensure their children's education. One woman told me very proudly of her teaching degree and how she had completed this degree three years previously at the age of 55.

P1) "And you know, beyond all understanding I did very well in that. So... I think I turned out well to be at least a woman..."

Despite this, she voiced her concerns about retirement and getting her daughter through school and being able to start her off in tertiary education. But the aspiration was clear, as well as the perceived importance of education.

P1) "I'm just trying to get Amy through high school. She started high school this year. To get her through high school as far as I can. And then maybe... first year university..."

One other participant emphasized the fact that she put effort into speaking to her children at least once a day over the telephone. She called her children every night because she knew the value of communication and that hearing their mother's voice was important to her children's well-being, their development and encouraged their general education. She poignantly pointed out the link between parental involvement and children's well-being as well as achievement.

P3) "As ek hulle nie op hoogte gaan hou nie met my stem nie, kan hulle 'n terugslag kry in hul skoolwerk... en om elke aand vir hulle hallo te sê, dis 'n versterking in hulle education, en hulle gesondheid."

Similarly another research participant had to insist that her son go back to Canada where he had been training. His school had given him permission to come home to South Africa to support his mother during the time of her illness, and initially he had refused to go back. However, his mother had explained that she understood the value of his education and her role in supporting him emotionally through his studies.

6.4.3) Emotional and Financial Responsibilities

A recurring theme throughout all five interviews included the financial and emotional support these women provided for their families despite the fact that they themselves were in need of support networks during this time. One woman exclaimed how she simply wanted to get back to work in order to pay for dolls and clothes for her two children. Another woman commented that she had been given one hundred rand, and that she had immediately gone to the shops to buy much needed shoes for her youngest daughter.

P2) “Ek dink aan my kindertjies. Ek was nogal winkel toe gewees, vir die enetjie ‘n paar skoentjies gaan koop, want sy het nie skoene nie. Iemand, iemand het my gebles... ‘n blanke tannie het my gebles... sy gee vir my ‘n honderd rand. Toe het ek dadelik vir my kind gaan skoene koop. Want (voice trembling) ek kry nou ‘n lift en ek kan nou vir haar die skoentjies inpack.”

A common sentiment also appeared to be the emotional support that families required from their mothers and wives. Two patients in particular expressed this very simply by saying that they had chosen to live, because their children needed them. This stresses the importance of a sense of purpose in each human being and possibly more so in the cancer patients’ experience.

P2) “Ek sal lewe, en ek sal vir almal hier wees... My kids need me. Ek kan nie doodgaan nou.”

P3) “Ek het my gesondheid gekies... toe het ek my bors laat gaan, en my man is oorlede, en my kinders is baie klein, en hulle het my baie nodig...”

Another participant also stated that she needed to remain positive and get through this experience, for the sake of her children.

P5) “Ek moet dit mos nou maar aanvaar. Ek moet mos daarmee saamleef, terwille van my kinders en my man... moet ek mos nou positief mos nou maar optree.”

6.4.4) Femininity

Being woman appeared to be intrinsically linked to society’s constructions of breasts as being vital in achieving an ‘appropriate’ level of femininity. In addition, women referred to their yellowed nails and their brittle hair, explaining how these reactions and results of treatments had made them feel less womanly.

P2) “Dis moeilik, want my hare breek af van die medikasie. My hare was so pragtig... en nou is hulle kort... het ‘n bietjie gegroei.... maar ek kan nie eers ‘n straightener aansit nie, want dis te gevaarlik. En nou moet ek dit kort knip.”

However, while nails and hair were spoken about, the idea of living with only one breast and what this would look like when wearing dresses and/ or other feminine clothing and how they would be perceived in social or work settings was of far greater concern for many of my research participants.

P1) “I love wearing dresses which open by my shoulders. I love that... And on Sunday night, I was lying in hospital and I was worrying about how I am going to look... what am I going to do... and will I ever look feminine again and all these wonderful things. I keep worrying now, how am I going to look when I go back to work?”

During the fourth interview, my research participant explained that she was not immediately concerned about her appearance when she first received her breast cancer diagnosis, but that she was in shock at her physique after the surgery had been completed. Unable to control her emotions, she cried as she described how she refused to even look at her own body now because it was too painful for her to acknowledge that she only had one breast. A difficult process towards acceptance in progress.

P4) “Ek kyk nou nog... ek kyk nie hier nie (demonstrates breast area) want as ek daardie kant toe kyk, dan loop die tranne, want dit is nie vir my lekker nie (Begins to cry). Want die ding is ook, ‘n mens kan nie klere aan... jy kan niks aantrek nie, weet, wat jy gewoon was om te dra nie want hier is... net hierdie kant is ‘n bors en hierdie kant is NIKS nie. (sobbing).

One patient who had shared information about the abusive relationship with her husband described how she had automatically assumed that he had decided to leave her due to the fact that she would no longer be sexually desirable for him. She explained that she thought he viewed her as a lesser woman as a result of her breast removal.

P2) “En ek het gevra, wat het hy gedink? Dat ek nou ‘n halwe vrou is? Of wat??”

A more positive take on what it meant to be a woman was expressed by my third interviewee. She went into great detail about her physiotherapy appointments and the exercises which she was tasked with. She explained with great pride that she stuck to her exercise routine every day and even demonstrated for me what this entailed. It became very clear during this conversation that she did not rely solely on medicine and hospital staff to bring her body back

to health, but rather held herself accountable too, and felt that she was also responsible for her own progress.

6.5 Conceptualizing Disease and Cancer

A prominent theme occurring throughout most of the interviews revolved around how patients, family members and friends reacted to the breast cancer diagnosis. Most women had to reassure their loved ones that breast cancer did not necessarily mean imminent death. The research participant, whose husband left her after hearing of her diagnosis, explained that she understood his actions given that people often misunderstood cancer as an acute disease rather than seeing it as a manageable and sometimes treatable chronic disease.

P2) “Kyk, hy het gedink ek gaan nou dood. Maar as mense hoor van kanker dan dink hulle ‘n mens gaan nou dood. Hy het nie met baie kanker mense kommuniekier nie. Ek weet... ek het gesien waardeur hy gaan. Toe sien ek: die word is kanker, maar dis net dood wat jy daaronder sien.”

This was reiterated by another patient who explained how her son called her from Canada where he was studying, to ask her whether this diagnosis meant that she was going to die. He had immediately associated cancer with death, which appears to be a common perception.

P4) “...toe my seun hoor ek het borskanker, toe bel hy my, toe se hy ‘mammie, gaan jy dood?’”

Apart from equating cancer with death, the different ways in which the disease was conceptualized emerged during interviews. One woman verbalized this particularly well, mentioning that it was not only cancer treatments that made a person ill. She explained that it was the questions people asked her and people telling her how sick the chemotherapy would make her which instilled a fear in her, but that it was in fact these feelings of dread which made her feel ill.

P2) “Maar dis eintlik mense wat vra: hoe gaan dit met die chemo, of hoe gaan dit met dit en dit... DIS wat eintlik maak jou siek. Iemand sê vir my, dis die chemo wat ‘n mens so siek maak... maar dis die bang gevoelens wat jou eintlik siek maak... Die gedagte is wat ‘n mens siek maak. En ek het dit eers self ervar... dit maak siek.”

6.6 Patients' Needs and Unanswered Questions

Several suggestions emerged regarding the cancer experience and what could be done to make this an easier or more comfortable process.

Most of the women emphasized the need for better and repeated information, as they felt they had been in a state of too much shock initially to understand and absorb much of what doctors or nurses were explaining to them. These needs were very specific and my research participants highlighted that they wanted to be informed of everything at every stage. They frequently mentioned how they wished they had known more about what the chemotherapy would do to their bodies – being told that they would feel nauseous and sick was not acceptable to many. They wanted to know exactly why the chemotherapy was making them feel this way.

Another query in connection with the chemotherapy was with regard to the amount of sessions each woman needed. One patient exclaimed that she was sent for six chemotherapy sessions but that she did not know why it had to be specifically six sessions. Another patient also felt frustrated about her radiation therapy. She explained how out of control she felt because doctors at Somerset Hospital had informed her that she would only need chemotherapy and not radiation therapy. However, now she was back in treatment and she wanted to know why she had to undergo the additional radiation therapy. She explained that she felt unable to ask her doctors about this because they did not give her any straight answers. She was also unsettled because she had experienced great difficulties communicating with her doctors due to infrequent appointments. Also, in the state hospital context, there had been little or no continuity – she was seeing a different doctor every time she had an appointment which did not sit well. This has made her feel that her doctors are not being honest with her, and that they are hiding the fact that some cancer has remained in her body and that this is the reason that she now has to endure radiation therapy.

Another interviewee told me that she also needed to receive radiation therapy, but that she had not been aware of the fact that patches of her skin would fall off and that she was incredibly alarmed when this began happening. She reiterated what others had said about wanting to know more about the treatment processes and how these would affect her body.

Additional concerns emerged around the medication that had been prescribed post-chemotherapy and radiation therapy. Women seemed very confused about why they should have to take medication over the following five years after having received so much treatment.

P3) “Dokter het my op ‘n pilletjie gesit vir vyf jare... as ek dan nou so gesond is, hoekom moet ek medikasie kry?”

Patients also emphasized that it might be nice to have frequent support group meetings at their respective care-homes to help understand and learn from others going through similar experiences.

P4) “Weet jy wat ek sal ge-‘like’ het – as hulle miskien ‘n support group kan stuur hiernatoe wat met jou HIER kan kom praat... op a gereelde tydperk...”

Two women I interviewed emphasized the fact that it was difficult to simply strike up such conversations with another person and that a group counsellor could potentially help make this a smoother and less inhibiting process.

P2) “...to talk about how you feel, talk to heal the heart... dis baie swaar!! Vrouens voel dit is ‘n skande... hulle is te skaam.”

Overall, it appeared that women would have liked more re-assurance and more information about their treatment and their breast cancer, consistently throughout the treatment trajectory and to talk about the process more frequently.

Chapter 7: Discussion

Themes emerging from the open-ended research questions emphasized various as well as common experiences, outlooks and coping mechanisms made by women diagnosed with breast cancer (Avis, Crawford & Manuel, 2004). This emphasizes my theoretical starting point which highlighted the fact that lived experiences are heterogeneous in nature and that recognizing this and addressing the differences in experiences amongst breast cancer patients is essential to feminist research.

The stratification of heterogeneous societies most commonly separates dominant from different and/or subordinate. Essentially, what this means is that males and females of dominant social groups hold greater amounts of power and added rights and responsibilities than do members of socially-deemed subordinate groups (Lorber, 1994). As was discussed in the literature review, society defines social constructs and categories by setting unspoken rules and expectations. This includes being categorised and judged on physical appearance. In terms of my research participants, this is linked to ideas of what it means to be feminine. According to theory, having a breast or both breasts removed seems to indicate that hegemonic femininity is not achievable for these women and results in feelings of being defeminised and desexualized. The socially constructed notion that only one true feminine ideal exists, greatly influences general perceptions of what it means to be a woman. In addition, lived experiences are conditioned by a matrix of power, including intersecting factors of race, gender and class.

The social construction of gender also appears to be supported by larger social systems such as the medical sphere, which encourages women to seek reconstructive surgery to better fit in to social expectations of what a woman should look like and to reaffirm gendered identities and roles as mothers, carers and supporters. All five interviews highlighted patriarchal notions of society, where husbands were perceived as the head of the household, despite the fact that these women were primary earners and caregivers.

With regard to these social constructs, participants were sensitive about their self-image and identity as women. In addition, women attempted to assign significance to previous actions in order to explain the cancer in their bodies. One patient wondered if it had developed as a result of her husband's abuse, while another continuously questioned why god had let this happen to her.

Previous research indicated the importance of support in helping women to successfully cope with breast cancer. Women's support needs varied considerably depending on the stage and phase of the breast cancer trajectory. As such, it was vital to comprehend the ways in which women conceptualized support, in order to appropriately develop interventions (Dickerson, Alqaissi, Underhill & Lally, 2011).

Various ways of coping were exhibited. These included accepting or avoiding the reality of a diagnosis. The types of support needed by women also varied and depended on the type of treatment they were experiencing, the amount of time that had elapsed since diagnosis and also which support structures were available to them.

Viewing cancer as a long-term illness, and understanding women breast cancer patients' experiences within a larger framework of patriarchal, hegemonic social structures, was vital in enabling my understanding of the necessity for adequate support structures for individuals battling with the disease.

Interventions in terms of clinics and accessibility to screening facilities and support systems are needed. Current statistics, produced by quantitative research, may be skewed as a result of lower class individuals being less able to access such health facilities. This impacts on research and knowledge around breast cancer, as well as our understanding of how it affects women differently.

The fact that one in every twenty-nine women is diagnosed with breast cancer also means that one in twenty-nine families suffer the loss of mainstay – namely mother, wife, chief supporter and caregiver of family. As such, families are often dependent on the physical and emotional health of the woman, who represents the centre of the family. Thus, women were not only fighting death but also trying to maintain a stable family. In light of this, it should be important to consider how much counselling family members receive. As such, it was hugely stressful to be away from home. In response to this, some participants mentioned how the breast cancer experience had been beneficial in the sense that they were made aware of better prioritising their own health instead of constantly caring for others and in changing their perceptions with regard to what was most important in their lives.

Women placed greater priority on themselves and their health. In essence they invariably chose life over a 'perfect' body, developed a greater appreciation for life, and felt reassured through their faith in God. Research participants with a deep faith in and a close relationship

to God seemed to have greater/ deeper inner resources to rely on. These women were far more able to adjust to the breast cancer diagnosis and maintained a positive outlook on life. Most participants had changed their perspectives regarding family dynamics and friendships and had gained insights into what they valued most about their lives (Arman & Rehnsfeldt, 2003). In addition, there is a need to mitigate against the loss of pillars of strength such as family and community.

Although discussions around breast disease and women's bodies would have been taboo to discuss so openly a few decades ago, public attention has increased. It is encouraging to observe a shift in this regard, however, improvements also need to be made in terms of information gained around various racial and class sectors. There is a need for a greater awareness and for education around breast cancer in rural and outlying areas. Emerging suggestions by research participants were that survivors, like themselves, get roped in, in their communities to 'pay it forward', share their experiences and offer an open ear to newly diagnosed women and that the idea of support groups be extended and rolled out systematically. CANSA appears to have the approach, but more well-trained and experienced counsellors are needed. Psycho-social support can help patients to make sense of their diagnosis without threatening their self-integrity. However, it must be said that it did NOT appear as though any of the ladies interviewed saw themselves as victims and I believe that this is testament to the fact that CANSA's support structures work.

In at least two cases (research participants four and five) concerns around the lack of information regarding their treatment, feeling out of control with regard to treatment decisions, and not feeling secure enough to voice their discomfort with being treated in certain hospitals, emphasized the paternalistic model in medicine. Namely that women's involvement in their own medical treatment processes of their bodies is often marginalized. During interview number four, a recurrent question, articulated by my research participant was why she needed radiation therapy. This was a worrying/ concerning pointer to 1 of 2 things, or a combination of the two: her medical professional neglected to explain that no two cancer diseases are the same, but rather an individual affliction. And/ or that the patient had information overload or exhibited strong denial. Furthermore, insecurities are heightened by unresponsive doctors and unsupportive communications and interactions had negative impacts on patients' adjustments. This highlights the power dynamics between female patients and male health practitioners and emphasizes the role of race and class in South African society.

Furthermore, women's illness anxieties are often neglected during treatment. This is evident due to the fact that previous work focuses largely on quantitative data, ignoring lived experiences. Vital to understand is that a breast cancer patient's healing process needs to be addressed in a holistic manner, rather than solely focussing on the physical body. The stress that overwhelms breast cancer patients needs to be alleviated or reduced and managed better. And the fact that waiting for information, and waiting for treatments are two of the most stressful phases in this process need to be taken into consideration. Additionally, illness anxieties often inform adjustment processes to breast cancer diagnoses and treatment, and can potentially cause a negative perception of the self. Counselling and pre-social support is felt to be very empowering to increase the fortitude/ resilience in the monumental effort of leading a life of quality in the face of a life-threatening disease.

All research participants were matriarchal type women who defined their worth according to roles of wife, mother, worker, and do-er rather than by their looks – and yet I got the feeling that they suppressed their own needs with regard to their body image and the importance of their breasts.

Much of the underlying information with regard to emotional state was conveyed in the pitch, timbre, volume and speed in and with which the answers and responses were verbalized. This was especially the case for participant number four who's timbre in voice changed notably when she explained the possibility of breast reconstruction; and in the case of interview five, throughout which the breast cancer patient became very emotional, particularly during conversations about her husband.

My interest in their stories and curiosity about their experiences as breast cancer survivors appeared, to me, to be appreciated by interviewees. It seemed that there was a great need to verbalize, share, articulate, and vent, and in some cases the interview process appeared to help participants reflect on and make sense of past experiences. It is felt that this expression of concerns in itself was significant for the ladies. Not only were they afforded a chance of formulating, verbalizing thoughts and feelings but some of these may have been crystallized during these interview sessions. The clarity with which they were able to express themselves was seen to be proof of the empowerment which language in itself provides.

It is also my distinct impression that the opportunity of interacting with an objective outsider MAY have been another therapeutic exercise. I am raising this because I wish to emphasize the significance of the one-on-one counselling need. Additionally, there is a great need to

have the same person(s), not only in the medical team, but during the psychosocial support efforts too, because a trusting relationship between patient and ‘carer’/ counsellor is absolutely key.

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Chapter 8: Concluding Remarks and Future Directions

The journey of writing this dissertation began in January of 2012 when I discovered a research topic submitted by CANSA to the UCT Knowledge Co-op, requesting research to be conducted with breast cancer patients about their experiences awaiting treatment. After contacting Barbara Schmid of UCT's Knowledge Co-op and an initial consultation during which I explained my interest in taking on this project for my honours research thesis, a meeting between Barbara Schmid, my supervisor Dr Adelene Africa, Dorothy Du Plooy from CANSA and me was set up. Soon hereafter it was agreed that my main research question would focus on breast cancer survivor's experiences of treatment and that sub-themes would explore the impact of breast cancer diagnoses and treatments on feminine identity in order to link CANSA's research interests with my interests as a Gender Studies student.

The fact that my research was to contribute to CANSA's knowledge base as well as towards the completion of my honours degree was nerve-tingling, to say the least. However, throughout the year and throughout my research process, this team of women provided academic as well as emotional support whenever I was confronted with any questions or concerns. Each of them was easily contactable and I regularly received a telephone call or email from Barbara Schmid to check on my progress and to talk about my experiences and feelings towards this research. I appreciated all of these efforts tremendously. In addition, the fact that I was involved in participative research with CANSA meant that recruitment of research participants was made relatively easy through CANSA's permission to contact breast cancer patients residing at CANSA care homes. This would certainly not have been the case if CANSA had not been involved in this process.

This report started out with a literature review, pin-pointing dominant themes in previous research around gender, social constructions of femininity, and breast cancer. Questions, arguments and theories which emerged, and which seemed important to my research, included issues around the gendered experiences of breast cancer patients as well as acknowledging and addressing differences in experiences amongst these women, influenced by factors such as class and race.

My thesis then continued with a section on background, introducing CANSA and the Knowledge Co-op as partners in this research process as well as giving a brief overview of my personal experiences and reasons for wanting to conduct this research. Taking all of this

into account, a rationale for linking breast cancer research with feminist studies was provided and a main research question and two sub-questions were formulated.

How to conduct my research in a way that would uncover women's gendered experiences, as well as emphasizing that women's lived experiences are heterogeneous, was informed through core readings by feminist writers: Palmary (2006), Patai (1991) and Bhavnani (1994). These also assisted in my decision to use the semi-structured, in-depth interview method to generate my data. Furthermore, this feminist theory provided insight into the importance of recognizing my own positionality and the micro-politics due to the fact that I am a young, white, English-speaking, university student from a privileged background and I have not experienced what it is like to be diagnosed with or treated for breast cancer. These were important considerations to make as they most definitely influenced the connection established between research participants and myself and no doubt affected the knowledge that was produced during interviews. The issue of my positionality was not as easily negotiated as I had hoped. The biggest hurdle emerged as a difficulty in communication due to the language barrier. All except one of my interviews needed to be conducted in Afrikaans, which is the mother tongue of all of my research participants. Due to the fact that I understand Afrikaans on a third language basis, conducting the interviews posed quite a challenge for me. Nevertheless, as the interviews moved along and the more interviews I conducted, the better and the smoother this experience became.

Having said this, however, all patients shared an incredible amount of information about their lives with me and thanked me profusely towards the end of their interviews for having spoken to them and for showing interest in their stories. I felt that despite the language barrier, research participants were willing and eager to put differences with regards to age, class, and race aside and engage and connect on a purely human level. I truly believe that their experiences with breast cancer, coming to terms with issues of mortality and gaining insights into what they valued most about their lives, combined with their trust that I was genuinely interested in their experiences, enabled us to establish a comfortable connection.

After conducting these interviews, transcribing them and translating them into English, the information was reviewed using a thematic analysis. This was another difficult task because I felt unjustified in narrowing down these five lives and the wealth of information and experiences that had been shared with me into a few common themes. However, the most dominant and very important themes emerging from this data included women's experiences

of cancer and its treatment, their sources of support and coping mechanisms, perceptions around feminine identity, as well as patients' needs.

I consider this research to be new and important knowledge because it emphasizes the need to understand women breast cancer survivors' experiences on an emotional level as well as on a physical level and highlights how these experiences are gendered. Being gendered as women informs the experiences of breast cancer patients to a great degree and it is vital that we take gender seriously when developing better treatment policies and advocating for social transformation.

On the basis of what this thesis has achieved, potential future considerations could include researching current education and awareness campaigns around the issue of breast disease in urban and rural areas in order to have a more accurate idea of breast cancer prevalence in various population groups. New ideas and directions for research could investigate the role of breast cancer survivors in giving back through voluntary services, by sharing their experiences and offering an open ear to newly diagnosed women in their communities.

In addition, it could be useful to conduct comparative research to investigate different ways of coping, using women who manage their diagnoses and treatments relatively well as a measure of better informing the adjustment processes of women who struggle with these (Avis, Crawford & Manuel, 2004).

Further areas which have been left largely unexplored and which could be investigated in future research include a better understanding of how factors such as race, class and gender intersect to create various experiences of the breast cancer trajectory.

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Appendix A: Interview Questions

- 1) Opening question: Could you please think back to when you were first being diagnosed. What was that experience like?

Additional questions used as needed during interviews:

- 2) Can you tell me how long after receiving surgery you were able to start radiation therapy?
- 3) What were the reasons for this extensive waiting period?
- 4) Thinking back to that period between surgery and radiation therapy, can you tell me what that experience of waiting was like for you?
- 5) Did it have an impact on your physical and emotional strength? Could you tell me a bit about that experience?
- 6) How did this waiting make you feel towards the health system?
- 7) Can you tell me how you dealt with your diagnosis on a day – to – day basis?
- 8) How has the diagnosis changed the way in which you perceive your body?
- 9) How did the diagnosis make you feel about yourself?
- 10) How has fighting breast cancer impacted on your experience of being a woman?
- 11) Could you tell me a bit about your experiences in terms of telling friends and family about your diagnosis?
- 12) How did their reactions impact on your experience?
- 13) Are there any ways in which you believe your experience could have been made easier to deal with?

Appendix C: Consent Forms (Example and Signed Copies)

Consent form – English

University of Cape Town

Consent to participate in a research study:

Exploring the experiences of breast cancer survivors at various stages of treatment: An analysis of the constructions of breast cancer and of femininity.

Study Purpose

You are being asked to participate in a research study being conducted by a student researcher from the University of Cape Town, conducting an Honours research thesis. The purpose of this study is to explore survivors' experiences of breast cancer and breast cancer treatment, specifically how women experience the waiting period between surgery and radiation therapy and also to understand how breast cancer diagnoses and struggles with breast cancer shape perceptions of femininity.

You are being invited to participate in this study because you reside at one of CANSAs interim homes and have made the experiences which I am interested in.

Study Procedures

If you decide to participate in this study, you will be interviewed for between 30 and 60 minutes. The interviews will address your experiences of breast cancer and breast cancer treatment.

All information obtained from you will be kept strictly confidential, and your name will not be associated with the information that appears in my report.

Possible Risks

There are no known risks specific to this kind of study participation.

Possible Benefits

It is my hope that information gained from this study will help to inform the development of necessary emotional support and advocacy for additional capacity for treatment.

Alternatives

You may choose not to participate in this study, and this decision will not affect your relationship with the clinic, hospital or home in any way.

Voluntary Participation

Participation in this study is completely voluntary. You are free to refuse to answer any question. If you decide to participate, you are free to change your mind and discontinue participation at any time.

Confidentiality

Information about you obtained for this study will be kept confidential. Your name and other identifying information will not be kept with the interview information. It and this consent form will be kept in separate, locked file cabinets, and there will be no link between the consent form and the interview. The information obtained from the interview will not be made available to anyone else. Any reports or publications about the study will not identify you or any other study participant. I would like, if you agree, to tape-record this interview, as it makes it easier for me to be sure that we have correctly written down what you have told me. As soon as I have listened to the tape and corrected my notes, the recording will be destroyed. Until then, it will be stored either in a locked filing cabinet or on a password-protected computer to which only I will have access.

Questions

Any study-related questions, problems or emergencies, questions about your rights as a study participant, comments or complaints about the study may be directed to the following researcher and supervisor:

Anja Mulder 083 957 0324

Dr. Adelene Africa 021 650 2971

I have read the above and am satisfied with my understanding of the study, its possible benefits, risks and alternatives. My questions about the study have been answered. I hereby voluntarily consent to participation in the research study as described.

Signature of participant

Date

Name of participant (printed)

Witness

My interviews may be recorded to assist the interviewer with remembering the information. The only person who will listen to the tape is the interviewer. After s/he has listened to it, it will be destroyed. Information from the interview will be recorded anonymously.

I agree that the conversation may be recorded.

Signature of participant

Date

Name of participant (printed)

Witness