

Younger women's experiences of the psychosocial impact of breast cancer:

Diagnosis, treatment and beyond

By

S'thembile Nontobeko Mjadu

Supervised by Professor Inge Petersen

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DECLARATION

I, **S'thembile Nontobeko Mjadu** (Student Number: 204524996) hereby declare that I am aware that plagiarism is academically unacceptable and as such I have utilised the American Psychological Association's format to acknowledge all sources used. This dissertation therefore represents my own work, unless otherwise indicated in the text.

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ABSTRACT

Using the biopsychosocial model and the Epigenetic principle, this study looked into younger women's experiences of the psychosocial impact of breast cancer at diagnosis, treatment and beyond the breast cancer experience. Case study methodology was employed and five women between the ages of 20 and 40 were interviewed on their experiences using the semi-structured approach to interviewing. The knowledge gained was analysed thematically. Results of the study revealed that breast cancer posed major psychosocial challenges for these young women as they attempted to negotiate the illness experience with the activities developmentally appropriate to their life stage. Developmentally relevant challenges were expressed in the areas of work, childrearing and partner-relationships and it was evident that spirituality and positive social support networks such as friendships and church groups played a significant role in helping individuals cope with the process, and emerge from it with an increased value for life.

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CHAPTER ONE

ORIENTATION TO THE STUDY

1.1. Introduction

Cancer is increasingly becoming a public health problem, affecting the young and old, amongst both males and females. According to the Cancer Association of South Africa (CANSA, 2005), more than 10 million people worldwide are diagnosed with cancer every year. The Cancer Association of South Africa (CANSA, 2005), further estimates that approximately 1 in 4 South Africans may be at risk of becoming a cancer statistic during the course of their life.

Among the different forms of cancer, there is cancer of the skin, cervical cancer, prostate cancer, lung cancer and breast cancer, to mention just a few. The current study focuses on breast cancer, with particular emphasis being on younger women's experiences of the psychosocial challenges posed by receiving this diagnosis, having to undergo treatment and also looking beyond the diagnostic and treatment phases.

Breast cancer has been found to be more prevalent in women at 16.6 % (Vorobiof, Sitas & Vorobiof, 2001) as compared to the estimated 1% of the male population (Sadovsky, 2003). For a long period of time, breast cancer has been considered the second leading form of cancer in women (with cervical cancer being in the lead). It is however, being increasingly documented that this trend has shifted, and in South Africa, breast cancer has overtaken cervical cancer, with 16.6% of women being diagnosed with breast cancer (CANSA, 2005; Keeton, 2003;

Vorobiof et al., 2001). A study by Mqoqi, Kellet, Sitas and Jula (2004) found the estimate of cervical cancer prevalence to be that of 1 in 31 in the year 1999, placing cervical cancer second after breast cancer.

These overall breast cancer statistics do not however imply homogeneity amongst women as these estimates vary across different racial and population groups. Vorobiof et al. (2001) maintain that breast cancer is the most common cancer among Asian and White women in South Africa with estimated prevalence rates of 24.4% and 17.9% respectively. The aforementioned further indicate that for women of mixed race and women of African descent, breast cancer has however, for some time been documented as being experienced mainly as the second most common cancer at 18, 2% and 13, 4% respectively, with cervical cancer being in the lead.

Looking at the variation of breast cancer demographics cross-racially, specifically in South Africa, presents an interesting dynamic. Vorobiof et al. (2001) indicate that the lifetime risk of developing breast cancer varies from a low of 1 in 81 African women to a high of 1 in 12 white women, with the stage and age at diagnosis also differing. Further, African women tend to be diagnosed with breast cancer at a more advanced stage while breast cancer in other groups tends to be detected in its early stages (Vorobiof et al., 2001). A possible contributing factor could be that of a lack of early detection due to a limited amount of tests carried out in public hospitals, as a result of the cost implications of testing procedures. There thus exists a great likelihood that individuals, who cannot access private care, are less likely to have the cancer detected sooner and that some might want to explore other treatment modes such as traditional healing before approaching Western health care (Schlebusch & Van Oers, 1999; Vorobiof et al., 2001).

While breast cancer amongst African women is still comparatively lower than the other race groups in South Africa, an increase has been noted, particularly among young black women (that is women, aged 40 and below) (Campbell-Gillies, 2003). This is a deviation from the long standing trend that assumed low breast cancer prevalence among women of African descent, especially at a younger age. There currently does not exist any explanation for this increase but may be due to the increasingly affluent lifestyles of a great percentage of young women which may include smoking and diet as well as to the role that immunosuppression by the HI Virus could play.

Breast cancer is a complex medical condition, from pre-diagnostic, diagnostic and treatment phases. Apart from the rigorous and invasive medical procedures, breast cancer presents challenges ranging from difficulty executing basic daily activities, to issues around fatigue, fear, finances, family problems, pain and spirituality (Campbell-Gillies, 2003; White & Macleod, 2002).

Evidently therefore, the illness goes beyond being an aspect of concern only within the medical domain (Rubin, 2001). The emergence and advancement of the fields of psycho-oncology and psycho-neuroimmunology bears witness to this assertion as it has aided the recognition and inclusion of the psychosocial morbidity associated with the diagnosis and treatment of breast cancer as part of a treatment plan. It is therefore with the aim of contributing towards this holistic understanding of breast cancer that the current study was conducted, seeking to explore the challenges posed by the diagnosis and treatment of breast cancer at a psychosocial level.

Joiner and Fisher (1981) assert that breast cancer diagnosis and treatment should be seen as an issue of rehabilitative concern with attempts at rehabilitation aiming to encompass a range of issues from the medical realm through to personal readjustment thus ensuring that health workers do not focus only on biological aspects of the disease but, address potential and occurring psychological as well as social issues.

While the majority of breast cancer cases are seen in women in their late 40's and above, the illness is however, becoming more common in younger women (Cancer Association of South Africa, 2005; Vorobiof et al., 2001). Given the paucity of research on younger women with breast cancer, particularly in the South African context, this study paid particular attention to younger women's experiences with regards to the psychosocial challenges associated with the diagnosis and treatment of breast cancer.

In addition, Turner, Wooding and Neil (1998) maintain that being diagnosed with breast cancer at a younger age is among some of the factors that contribute to the risk for psychosocial morbidity. This immediately raises concern, considering the fact that young women have a lot to deal with (especially in South Africa, with gender based violence, HIV/AIDS and unemployment) and since breast cancer incidence is on the increase, this might mean an added burden for younger women, for whom breast cancer is still regarded as uncommon.

Furthermore, Papalia and Olds (1992), maintain that at the developmental stage of young adulthood (that is between the ages 21 and 40), the following issues are of significance: work,

love, marriage, sexuality and parenthood. Receiving a diagnosis of breast cancer and having to undergo treatment in the midst of such developmental challenges might therefore be quite taxing on young women as they may have to face loss, the development of a low-self-esteem and other psychological and social difficulties. This research also includes an inquiry into women's social worlds because as much as individuals have a role to play in the construction of their lives and their views of the world, social factors are however, inherent components of human existence that interact in shaping and constructing our experience of our worlds. This view is supported by Rolland's family systems theory, which assumes that in order to fully understand illness, we need to incorporate other systems as well (Bellizi & Blank, 2006).

1.2. Problem Statement and Motivation

Studies aimed at gaining insight into the area of breast cancer diagnosis and its potential impact on individual's psychosocial well-being have aligned themselves with the dominant trend of placing greater emphasis on older women, that is women in their late 40's and women in their 50's. The current study utilised semi-structured interviews in seeking to deviate from this trend through focusing on the subjective experiences of younger women (21-40) with regards to the above-mentioned challenges of a breast cancer diagnosis. The knowledge gathered was analysed using thematic analysis with the view to providing detailed information whose lack may be detrimental to the provision of efficient client centred interventions from health professionals involved.

1.3. Aims and Objectives

This study was therefore aimed at understanding younger women's subjective experiences of being diagnosed with breast cancer in relation to the psychosocial impact the experience has on their lives. Sharing Information accessed by this study with health practitioners who may find themselves faced with the task of intervening at the social and psychological levels of survivors' functioning, would hopefully assist them in seeing their clients through to optimum wellbeing through the provision of relevant interventions.

CHAPTER 2

LITERATURE REVIEW

2.1. Part A: Biomedical Aspects of Breast Cancer

The broad concept “cancer” can represent anything from cancer of the throat to cancer of the skin. Starr and Targgart (2005) define cancer (regardless of what cancer it is) as a condition that sets in when cells in certain parts of the body start growing in a manner that is out of control. Hence, whatever form of cancer one is experiencing; the one common characteristic to the next person with cancer is that of an uncontrolled growth and spread of abnormal cells. Cells are the human body’s building blocks that interact to make up tissues, which further lead to the formation of the different human organs (Sherwood, 2001).

The formation of human organs is normally one characterized by an orderly and controlled growth and division of cells to allow for the formation of new cells, as and when needed by the body. There are however, instances where this process does not follow the ideal routine and this is where one would see for instance, new cells forming when they are not yet needed by the body or the old ones that are due to die not dying as they should (National Cancer Institute of the United States, 2004). This then results in an overgrowth of cells thereby forming a massive tissue known as a tumour (Shier, Butler & Lewis, 2004).

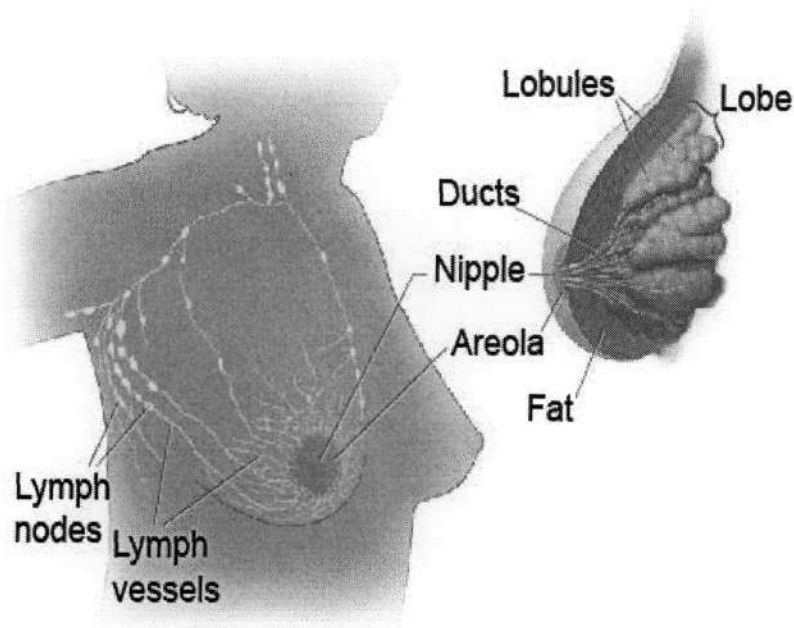
According to Dolinsky (2002), not all tumours are cancerous. The biggest question at this point is likely to be around how this is possible. Starr and Targgart (2005) address this question best through their distinction between invasive (malignant) and non-invasive (benign) cancer. Non-invasive cancer refers to a slow growing tumour that is confined to the site of origin and does not spread throughout the body but still requires investigation, as it can still be cancerous and lead to fatality if unattended. Invasive cancer on the other hand, refers to tumours that spread throughout the body or invade nearby tissues. Malignant (invasive) tumours are therefore the kind of tumours that demand much concern, as they are the core of what cancer is all about.

An aspect of note about malignant tumours is that they may not always be strictly confined to one group of cells or tissues but can break away and invade the bloodstream or other tissues thus leading to the formation of new tumours in a new organ and damage to other parts of the body. This process during which tumours break away and invade other organs is according to the National Cancer Institute of the United States of America (2004) known as metastasis. The metastasis process leads to the distinction between a primary and secondary cancer, with primary cancer referring to the original cancer and the secondary cancer referring to the organ to which the cancer has spread (National Cancer Institute of the United States of America, 2004). This spread of cancer to another organ does not give it a new name as it is still named after the part where it originated. For example, a cancer of the skin that has spread to the bone would be known as metastatic skin cancer, not bone cancer.

2.1.1. Breast Cancer

Breast cancer is a cancer condition that develops in either one or both of the breasts. A summarized pictorial representation of the breast follows, accompanied by a brief discussion on each of the structures and also their link to cancer of the breast.

Fig 2.1. Structure of the breast



From: <http://www.cancer.gov/cancerinfo/wyntk/breast>

2.1.2. Discussion on the Functional Structure of the Breast

The National Cancer Institute of the United States of America (2004) presents the structure of the each breast as being divided into 15-20 sections known as lobes. These structures (lobes) contain other smaller structures known as lobules, which are in turn made up of tiny glands that are able to produce milk. From the lobules, the milk produced

in the glands flows to the nipple via thin tubes known as ducts (National Cancer Institute of the United States, 2004).

As can be seen from the pictorial representation (Fig. 2.1), the breast is also made up of lymph vessels, which are thin tubes, meant to carry lymph fluid. The lymph vessels are directed to organs known as lymph nodes, found near the breast, underarm, above the collar bone, in the chest behind the breast bone and in various parts of the body (National Cancer Institute of the United States, 2004). In essence, the lymph nodes' primary function should be that of trapping bacteria, cancer cells and other harmful substances flowing through the lymphatic system. However, as mentioned previously, this orderly process does at times go wrong. For instance, lymph nodes can provide passage for cancer cells to spread rather than serving as an entrapment. An indication that cancer has spread to the lymph nodes is often that of the enlarging of the lymph nodes (National Cancer Institute, 2004).

2.1.3. Risk Factors for Developing Breast Cancer

A number of factors have been identified as increasing the risk of developing breast cancer (Rose, not dated). Below is a brief discussion on each of the most common risk factors:

- 1 **Gender-** So far breast cancer in women appears to be 100% more common than in men, with several indications of only 1% prevalence of breast cancer in men (Sadovsky, 2003). According to the National Cancer Institute of America

(2004) the simple fact that one is a woman is enough of a risk factor for developing breast cancer, with the main predisposing factor being the fact that women have more breast cells when compared to men, and these cells are continuously exposed to cell growth and division.

2 Age- According to the National Cancer Institute (2004), the risk of developing breast cancer increases, as a woman gets older. Keitel and Kopal (2000) also support this assertion when they maintain that when epidemiologists present statistics (for example 1 in 4 women is at risk of developing breast cancer), these statistics are meant to represent a lifetime risk, which increases, as a woman grows older. The Cancer Association of South Africa (2005) does however maintain that breast cancer is becoming far more common in younger women. This shift in trends thus suggests the importance of understanding that there are other factors beyond the age factor that, interact for breast cancer to develop.

3 Family History of Breast Cancer- Rose (not dated) maintains that a family history of breast cancer is a risk factor for developing breast cancer. Having a family history of breast cancer in this context refers to having perhaps had a mother, sister or daughter who has had breast cancer (especially at a young age).

4 Race-Literature demonstrates variations in cancer incidence among women of different racial groups. This variation appears to apply both locally and internationally. For instance, in the United States of America, White women are

more likely to develop breast cancer than are African-American women (American Cancer Society, ACS, 2004). In South Africa as well, Vorobiof et al. (2001) highlight that Asian and White women appear to be more likely to be diagnosed with breast cancer followed by mixed-race and African women respectively, who are more likely to experience breast cancer only as the second common cancer, after cervical cancer, although an increase has been noted among African women.

5 Personal history of breast cancer-Having a personal history of breast cancer refers to a woman having been previously diagnosed with breast cancer on either one or both of her breasts or women who have had ovarian cancer (National Cancer Institute,2004).

6 Estrogen- Estrogen's contribution to risk for breast cancer lies in prolonged exposure to the hormone. The greater the period of exposure to estrogen renders the woman more likely to develop breast cancer. Prolonged exposure to estrogen can be found in cases such as those of women who had their first menstrual period at an early age (before age 12 years) because the levels of estrogen in women increase during menstrual periods (Keitel & Kopal, 2000). Prolonged exposure can also come about as a result of delaying or never having children because when a woman is pregnant, menstrual periods and estrogen production are delayed until after pregnancy. Experiencing menopause late (after age 55) or taking hormone replacement therapy has also been found to increase women's

risk for breast cancer as both these factors contribute to an increase in the amount of time during which the body is exposed to estrogen (National Cancer Institute 2004).

7 Radiation therapy-Women who have been exposed to radiation during radiation therapy for either treatment of breast cancer or Hodgkin's disease may be at an increased risk for developing breast cancer, especially if this took place while they were still younger (National Cancer Institute, 2004). According to Fisher, Osborne, Margolese and Bloomer (1997), other forms of radiation, for instance being a survivor of an atomic bomb explosion may also be a risk factor for the development of breast cancer.

8 Alcohol-Although the relationship is not indicated clearly, alcohol use has however been pointed to as contributing to an increase in women's risk for developing breast cancer (Keitel & Kopal, 2000). A study by Aronson (2003) was able, through a combined analysis, to demonstrate that alcohol is a clear risk factor for breast cancer regardless of whether other confounding variables, such as personal history of breast cancer, are present or not.

What is important to note about risk factors for developing breast cancer is that these do not suggest that a woman will definitely develop the cancer. It is important to note that various factors may interact in predisposing women to the risk of developing breast cancer. Hence, when raising breast cancer awareness as well as when assessing women's

risk of developing breast cancer, it needs to be borne in mind that factors such as family history tell us only part of the story as one will at times find that women with more than one of the previously mentioned risk factors may not develop breast cancer at all (Dooley & Williams, not dated).

2.1.4. Detection and Diagnosis of Breast Cancer

According to Rose (not dated), screening for breast cancer is important, especially for early diagnosis, which is necessary for obtaining high cure rates. Thomson (1998) highlights possible signs and symptoms that one could look for in screening for the potential presence of breast cancer. It is important to note that these symptoms may not always indicate the presence of breast cancer. Hence further investigation to include or exclude malignancy is necessary.

- 1 Change in the shape and size of the breast.
- 2 Discharge from the nipple other than milk.
- 3 Puckering and dimpling of the skin.
- 4 Nipple inversion
- 5 Excoriation of the areola.

- **Mammogram**

Screening mammograms are X-rays of each breast taken with the aim of detecting breast malignancy. The breast is positioned between two plates for a number of seconds during the process of taking X-rays. According to Dolinsky (2002),

mammography can often detect tumours before the doctor or the patient is able to see or feel the changes. Thus mammography can aid detection to the level that has the potential to even phase out the development and onset of breast cancer. This is achieved through the detection of small groups of cancer cells in their earliest stages before they are enough to form a lump or a cancer that is capable of spreading to other parts of the body.

Mammography can also be utilized as a diagnostic tool, in which case it is referred to as diagnostic mammography. Ku (2001) does however maintain that the use of mammograms exposes women to the risk of cumulative radiation. This may be found to be particularly the case with women of a younger age, who are likely to have dense breasts that have a tendency to absorb more exposure radiation. Breast density also poses a limitation when it comes to mammography. Wysong (1999) supports that the greater the density of the breast, the less likely for the mammography test to be sensitive to the cancer. Albert and Schultz (2003) posit another shortcoming of screening mammograms as being that of requiring specialized equipment thereby imposing major cost on patients. This may particularly be a problem for a majority of South Africans who might not have easy access to oncology services and may not be able afford these specialized services.

- **Clinical Breast Examination**

Bedell (2000) recommends for women aged from twenty to forty years to have a clinical breast exam by a health professional every year, comprising of both systematic examination and palpation of the nipple, breast and lymph draining regions. Albert and Schultz (2003) also advocate for this screening modality maintaining that the method comes highly recommended as a method for detecting breast cancer for public health benefit, as it is inexpensive. In a study conducted by Dr Kolb (in Wysong, 1999), the examination managed to detect only 30% of breast cancer cases, which rendered its merits as a detection modality, rather questionable. The method is however; particularly useful for younger women for whom screening mammography might not be an option because of the risk of cumulative radiation (Ku, 2001).

- **Breast Self-Examination**

The ACS (2004) recommends that women in their 20's should start performing breast self-examination. The Society (ACS, 2004) recommends also, that women review their self-examination technique with their practitioner during the clinical breast examination in order to acquaint themselves with the different techniques and positions at which the examination can be carried out. This method is according to Ku (2001), useful particularly for the following reasons:

- 1 To detect any lumps that might develop during the period between annual mammography or clinical breast examination.

- 2 To familiarize women with their breasts thus helping them when they go for mammography as they would know how their breasts normally feel
- 3 And it is also of low cost and is noninvasive.

- **Ultrasound (sonography)**

According to (Dolinsky; 2002), an ultrasound is an imaging technique in which high frequency sound waves that cannot be heard by the human ear are bounced off tissues and internal organs, producing a picture called a sonogram. This method is not routinely used for screening however. It can be used to evaluate breast abnormalities that are found during a screening or a diagnostic mammogram or physical exam and can be a useful addition to mammography when screening women with dense breasts. This is according to Wysong (1999), due to the fact that the test becomes more sensitive to abnormality as breast density increases.

Sometimes an ultrasound is used as part of other diagnostic procedures, such as fine needle aspiration, also called biopsy, and involves the removal of tissue or fluid with a needle for examination under a microscope to check for signs of cancer (Dolinsky, 2002). The weakness of ultrasound is that it is not able to consistently detect certain early signs of cancer such as the tiny deposits of calcium in the breast (known as micro calcifications), which cannot be felt but can be seen on mammogram and can be an indication of the presence of cancer if they are in clusters (Dolinsky, 2002).

- **Magnetic Resonance Imaging (MRI)**

This method of screening for breast cancer is, according to the American Cancer Society (2007) and Rose (not dated), recommended for women at higher risk of developing breast cancer. The American Cancer Society (2007) maintains that this method utilizes magnets and radio waves with the aim of creating an image of a particular body part (in this case, the breast), ensuring early detection of the cancer. Women at high risk for breast cancer consist of women who have an inherited genetic predisposition in their genes as can be identified through blood testing on women with a strong history of breast cancer in their families. Rose (not dated), does however identify one shortcoming of this screening modality which he finds to be the fact that this test is not very specific, in that it can detect a handful of abnormalities, only to find that they are not malignant tumours, especially in younger women who may have dense breast tissue (American Cancer Society, 2007).

- **Biopsy**

Biopsy techniques refer to techniques that are utilised with the aim of confirming the diagnosis of breast cancer. These techniques include the following: Fine needle aspiration, core needle aspiration, incisional biopsy and excisional biopsy where a needle is inserted to draw substances from areas appearing abnormal through mammogram (Dolinsky, 2002).

2.1.5. Staging breast cancer

Physicians use the process known as staging in assessing the size and location of the patient's cancer. In other words, staging is for the purpose of assessing how big the tumor is and whether it has managed to spread from its primary site. Staging is important in facilitating the treatment process (National Cancer Institute, 2004). Staging is carried out through several tests that are able to help stage breast cancer. These may include clinical breast exams, biopsy, and imaging tests such as chest x-rays, mammogram, bone scan, CT scan, and MRI scan (Imaginis Breast Cancer Resource, 2004).

Imaginis Breast Cancer Resource (2004) outlines the following as the standard staging format. The letter T followed by a number from 0 to 4 describes the tumor size and whether it has spread to the skin or chest wall under the breast.

- 1 TX: Tumor cannot be assessed
- 2 T0: No evidence of a tumor
- 3 Stage I/ T1: Tumor is 2 cm or less in diameter
- 4 Stage II/T2: Tumor is between 2 and 5 cm in diameter
- 5 Stage III/T3: Tumor is more than 5 cm in diameter
- 6 Stage IV/ T4: Tumor is any size, has attached itself to the chest wall and spread to the pectoral (chest) lymph nodes.

2.1.6. TREATMENT OF BREAST CANCER

Breast cancer treatment takes into account the characteristics of and stage to which the cancer has progressed. The treatment of breast cancer can be divided into three forms namely localized, systemic and combination treatments, with different subtypes falling under each form of treatment.

- **Localized Treatment**

The main purpose of localized treatment is to treat the cancer with as minimal effect on the body as possible. The main two types of localized treatment are surgery and radiation.

(I) Surgery

A majority of women diagnosed with breast cancer often undergo some form of surgery at some point during the course of their treatment. According to an information brochure by the American Cancer Institute (2004), surgery aims at checking whether the cancer has spread to the lymph nodes, and removing as much of the cancer as possible. Surgery can also include breast reconstruction. There are different approaches that can be utilized for surgical purposes.

Breast Conserving Surgery (lumpectomy) - Also known as breast lumpectomy, breast conserving surgery involves the removal of the lump in the breast as well as some normal or healthy tissue on the margins of the lump, thus allowing women to keep their breast (American Cancer Society, 2004). By doing this, the

entire breast is therefore not removed as the name implies “breast conserving therapy”. Bedell (2000) recommends that lumpectomy be combined with radiation therapy in order to minimize and ultimately prevent recurrence. As mentioned previously, there are factors guiding the choice of treatment, being at stage I or stage II therefore predicts the potential effectiveness of lumpectomy. In other words, lumpectomy is often not recommended as the main option for women with advanced breast cancer (American Cancer Society, 2004; Apantaku, 2002).

Breast Removing Surgery (Mastectomy) - Mastectomy involves the removal of breast tissue involving either simple mastectomy (total) or radical mastectomy. The latter (radical) is however, being abandoned due to its drastic and deforming consequences (ACS, 2004). According to the ACS (2004) both mastectomies involve the removal of entire breast tissue but there are differences in how they are carried out. For instance, while simple mastectomy (total) is the removal of the entire breast excluding the pectoralis muscle (muscles that are attached to the front of the chest wall and upper arms, next to the breast), radical mastectomy on the other hand involves the removal of the entire breast plus the pectoralis muscle. The decision as to which mastectomy to undergo rests upon factors such as nipple involvement, tumour size and fear of recurrence (ACS, 2004). Mastectomy needs to be combined with radiation therapy as well.

(II). Radiation therapy or radiotherapy

Monesa (2003) defines radiation therapy as a treatment modality that utilises high-energy rays to destroy and shrink cancerous cells in order to stop them from growing and dividing. Breast cancer patients commonly receive radiation therapy to compliment other forms of treatment that they are receiving. In cases where radiation therapy patients have conserved their breasts or have had a mastectomy, radiation therapy is utilized with the aim of preventing recurrence (Bedell, 2000). The ACS (2004) indicates that the side effects of radiation therapy include fatigue, reduction in white blood cells, breast swelling or tenderness, feelings of heaviness in the breast, loss of appetite and an appearance of the breast that resembles sunburn.

- **Systemic Treatment**

Systemic treatment refers to the use of a combination of drugs to treat the whole body or system. According to Fleeger (in Breast Cancer.org, 2003), systemic therapy is necessary so that treatment is not only limited to the breast, in order to ensure that microscopic cancer cells that might have spread to other parts of the body are destroyed. There are three main types of systemic treatment, namely chemotherapy, hormone therapy and immune therapy.

(I)Chemotherapy

Chemotherapy involves the use of a combination of anti cancer drugs that go through the body to kill cancer cells (Dolinsky, 2002). These drugs can either be given before surgery so as to shrink the tumour thereby making it easy to remove or after surgery to reduce chances of recurrence. The higher the stage of the cancer, the more important it is that the patient receives chemotherapy with one of its major side effects being that of damaging some normal cells.

(ii)Hormone Therapy

This form of therapy is carried out through the use of drugs in patients with breast cancer related to estrogen. These drugs seek to suppress the estrogen hormone, which has the potential of making breast cancer cells grow provided the breast cancer reacts to estrogen (breastcancer.org, 2003).

(iii) Immune Therapy

Immune therapy seeks to assist the immune system in controlling or destroying cancer cells (breastcancer.org, 2003).

2.1.7. Follow-up after breast cancer treatment

Rubin (2001) alludes to how an improvement in breast cancer treatment has led to the disease being more of a chronic rather than a fatal illness thus making follow-up a necessity. Finishing the treatment course for breast cancer does not therefore mark the last appointment with one's physician, as patients are still required to present themselves

for follow-up appointments. According to Grogan, Rangan, Gebski and Boyages (2002), the purpose of follow-up is, to a great extent, determined by the extent to which the cancer has progressed at the time of diagnosis. These authors further maintain that follow-up presents an opportunity for the evaluation of early and late complications, for detecting new cancers, assessing treatment effectiveness and maintaining the doctor-patient relationship. However, Grogan et al. (2002), also indicate that follow-up is costly and has the potential of provoking anxiety around what the session might yield.

PART B: PSYCHOSOCIAL SEQUELAE OF BREAST CANCER

This section of the current chapter focuses on the review of literature on the psychosocial factors relating to the breast cancer experience. There is a large body of literature on the role that psychosocial factors play in the lives of the women diagnosed with breast cancer, both in terms of psychological and social factors such as stressful life events and or personality, as risk factors for developing breast cancer (Forsen, 1990). There is also a large body of literature focusing on the psychosocial impact of having breast cancer and its implications for treatment adherence and outcomes (Bleiker, Pouwer, Van der Ploeg, Leer & Ader, 1999; Forsen, 1990). There has been consensus across fields concerned with health and illness, that when a person's health is compromised the impact goes beyond the physical and challenges the individual's overall functioning which includes social, psychological, physical and for some, the spiritual world as well, and these interact and ultimately effect each other (Van Niekerk & Prins 2001).

The Farlex online dictionary (not dated) defines the psychosocial concept as that which comprises aspects of social and psychological behaviour. Together with the biological system, psychological and social factors thus make up the holistic view of humans. The psychological system has more to do with psychological health and illness. When one talks of distress within the psychological realm therefore, they would be talking about such factors as depression, anxiety, stress, self-concept, body image and self-esteem. The social system on the other hand would be more focused on relationships with family (children and extended family for some), friends, colleagues, dating/courtship and

sexuality, issues around fertility and gender role expectations, as well as one's cultural affiliation and economic standing within the broader social context.

2.2.1. Psychological Sequelae

According to Monesa (2003), receiving a diagnosis of cancer and undergoing treatment marks a time of heightened psychological distress, which is associated with the experience of feeling vulnerable, sad and anxious. Burnet and Robinson (2000) indicate an increased potential for psychological difficulties such as depression, anxiety, stress, depreciation in self-concept and body image perceptions to emerge. Burgees, Cornelius, Love, Graham, Richards and Ramirez (2005), suggest that younger age is a factor that often increases the risk for psychological distress. The following psychological sequelae are likely to occur as a result of breast cancer diagnosis and treatment.

2.2.1.1. Depression

Depression has been found to be more prevalent in women with breast cancer, especially in its early and terminal stages, with the possibility of persisting even years after diagnosis (Burgees, et al., 2005; White & MacLeod, 2002).

In presenting some of the most common indicators for the presence of depression, Monesa (2003), Kaplan and Sadock (2003) and Stonestreet (1985) agree on the following psychological and behavioural manifestations:

Feelings of guilt and worthlessness are amongst the features of depression and may come about as a result of the occurrence of events that individuals feel they are responsible for. These feelings of worthlessness are likely to be reflected in individuals' depreciating self-concepts. Individuals reach this depreciating explanation of their worth through internalising responsibility for bad occurrences. For instance, Champagne (2003), maintains that the most frequent initial response from partners, children, friends and family after a woman's diagnosis with breast cancer is one of shock and that the nature of this response soon gives way to a number of emotions including guilt as one of the main emotions.

This guilt can be evoked by a number of factors relating to the woman's context. For example, for a woman who has children, guilt can be precipitated and perpetuated by not being able to fully take responsibility for caring for her children thus making her feel not worthy of being a mother if she cannot fulfill duties related to motherhood (Champagne, 2003). The same may also be true for professional women who may feel that sense of guilt arising from perceived inadequacy at work since they might have to be absent from work a number of times.

This persistent perception of one as being guilty does, according to Loney and Radeziewicz (2000) often accompany constant questions of why one had to be the one with breast cancer. If there is not adequate information or support that removes the responsibility for the cancer from the woman herself then the alternative explanation of "it is because I am being punished for one reason or another" (guilt) may often be

adopted. Depression as a psychological state includes distortion or inaccuracy in one's cognitions about one's situation and the amount of control one can exert in an attempt to stabilise and ultimately master the situation. This distortion in cognitive functioning can also result in feeling sad and lonely due to blaming oneself for occurrences.

Physical and vegetative manifestations of depression include fatigue, difficulty with sleep, fluctuations in appetite and loss of interest in usual activities (APA, 2000; Kaplan & Sadock, 2003). Some of these manifestations present an ambiguity when it comes to breast cancer patients. For instance, fatigue can often manifest during the diagnostic and treatment processes of breast cancer as result of the pain and treatment side effects (Bennet, Goldstein, Lyoyd, Davenport & Hickie, 2004). This illustrates the need for a more holistic approach to assessment and treatment of our clients from both the medical and psychological point of view.

Beck (1976), cited in LoCastro (2003); Kaplan & Sadock (2003), and Monesa (2003) identify the following common factors that generally predispose individuals to depression:

- 1 Biological factors such as neurological abnormalities
- 2 Genetic factors identified through studies of families, adoptions and twins
- 3 Psychosocial factors such as life events and environmental stress, whether a single one of overwhelming magnitude or multiple ones occurring one after the other.

- 4 Cognitive distortions, personality and psychodynamic factors
- 5 A life-threatening physical illness or abnormality.
- 6 Situations that have negative impact on self-esteem
- 7 Inability to achieve one's goals or the lack of resolution in the face of a situation perceived as insoluble.

Although the current study is concerned with breast cancer which is a physical illness, the broader framework for this study, which is the biopsychosocial approach, should be kept in mind thus not only allowing one to only look at breast cancer as a physical illness but also bearing in mind that individuals function holistically. Hence some of the predisposing factors listed above might be in interaction with the process of breast cancer, diagnosis, treatment and recovery in influencing the onset of psychologically and socially challenging states among women diagnosed with breast cancer.

Breast cancer is indeed what Monesa (2003), terms "Challenging reality". It is often unexpected and requires huge adjustment and negotiation of one's roles and routines, ranging from the procedures that need to be carried out for diagnosis, treatment and follow-up purposes to sometimes excruciating pain that disrupts the smooth running of daily activities of the household and work. Women diagnosed with breast cancer may also blame themselves for the cancer and its impact on their physical abilities. In the face of intense physical pain, women might also develop an underestimation of their ability to cope and live beyond the cancer, feeling that they cannot do anything to help the situation and seeing the cancer as marking an end to their life.

According to Monesa (2003), depression amongst cancer patients may also be a response to loss. What is interesting about the concept of loss within this context is that it can either be a real or perceived loss. Day (1979), made an interesting observation that in one's life, familiar objects and surroundings grow to become an integral component of one's existence and these include things such as familiar sights, sounds, touch, home, personal belongings and family members which may all form part of a terrible loss as one leaves these surroundings for a health care site.

This perceived loss of significant others may also be a real one as intimate relationships may become more difficult and social contacts may withdraw as well (Monesa, 2003). For some there also exists the threat of a temporary or permanent loss of employment. This becomes an interesting and critical dynamic as one can observe that world wide and more so in South Africa; women are rapidly gaining and embracing their independence. As Bohnet (1986), suggests, whether perceived or real, the loss of independence may become a difficult process in the case of a self-reliant and autonomous individual, as it is more likely to yield questions about self-worth and control among these women.

The sense of loss can also extend to the possibility of loss of the breast, which is a representation of femininity. This aspect will receive more attention under the body image section. Another perceived loss amongst breast cancer patients may be that of imagining impending death (loss of life). According to Horowitz (1979), thoughts around death precipitate a weak self-image where one sees themselves as vulnerable and

helpless. According to Fetsch and Miles (1986; in Monesa, 2003), experiencing loss is a painful process that evokes feelings of helplessness, which can be a feature of an existing depression or a mediating factor in the onset of depression.

2.2.1.2 Anxiety

Anxiety occurs across different phases (pre-diagnostic, diagnostic, treatment and post-treatment phases) of the breast cancer experience. Lyons (2004) indicates that at the time of screening for breast cancer and awaiting results, pre-diagnostic anxiety becomes a concern of clinical significance, as individuals start anticipating positive test results. This might be much more so for women already anticipating diagnosis due to the presence of risk factors such as family history.

Loveys and Klaich (1991) observe that the diagnostic and treatment phases do however, mark the most anxiety-provoking phase in the face of breast cancer. Lyons (2004) indicates that the crucial factor that is likely to evoke anxiety during the diagnostic phase and that tends to carry over throughout the process is that of a preoccupation with what will happen if the test results come back positive and also how the individual interprets the diagnosis and its likely consequences.

A study by Jacobsen, Bovbjerg and Redd (1993) on patients receiving chemotherapy for breast cancer revealed that a great proportion of the anxiety occurring during the treatment phase is largely due to the anticipation and expectation of negative side effects of treatment. These authors found that patients had anticipatory anxiety in relation to

breast cancer either because it was their first experience of the treatment and they had heard a lot of negative side effects or they had experienced treatment before and were anticipating the same negative side effects as previously.

Jacobsen et al. (1993) maintain that previous exposure to or lack of treatment experience are not the only likely explanations for heightened anticipatory anxiety since individuals' pre-morbid proneness to anxiety (trait anxiety) in situations deemed as threatening is also likely to contribute, regardless of whether one has had any personal experience with that particular stressor.

Jacobsen et al. (1993) and Northouse and Swain (1987) also observed that younger breast cancer patients often experience more intense levels of anxiety compared to older patients. These authors maintain that this is largely due to younger women perceiving themselves as more vulnerable to the potential disruption that treatment can impose on other areas of their lives such as careers, social, sexual and reproductive functioning.

Once treatment comes to an end one would expect that life goes back to normal and that individuals instantly feel physically better but there still has to be follow-up sessions in order to keep the potential for recurrence in check. According to Grogan, Rangan, Gebski and Boyages (2001), follow-up sessions are often anxiety provoking as women anticipate or are confronted with uncertainty and indications for recurrence, which can sometimes be a false alarm. Apart from follow up after the end of treatment being a potentially anxiety provoking exercise, the sessions are often reassuring as the cancer remains under

constant monitoring. However, the cessation of this monitoring can also take away this reassurance and can evoke fears. Furthermore, a slight feeling of pain may evoke sudden anxiety, as the concerned woman may worry that the pain might signify a recurrence of the cancer.

2.2.1.3. Stress

Stress symptoms amongst breast cancer patients seem to come about as a result of the frustration brought about by the diagnosis, with just about every area of life needing sudden adjustment. Aspects such as personal relationships, careers and finances (insurance and medical aids) are likely to become problem areas as one attempts to make meaning of and adjust to the diagnosis, symptoms, uncertainty and the treatment of breast cancer (American Psychological Association Help Centre, 2004).

Greenberg (2002) defines stress as a state whereby individuals experience demands, pressure or force as being beyond their resources to cope. The most critical aspect with stress is how individuals perceive and consequently respond to the situation they are faced with (Greenberg, 2002). Olivier (2002) identifies a variety of sources for the onset of stress. Amongst these are a threat to health and survival, a preoccupation with situations that are out of one's control and also living and or working under harsh conditions.

According to Greenberg (2002) stress manifests physically, psychologically and behaviourally, to include things such as disturbed sleep, aggressive behaviour, poor

eating habits, fatigue and withdrawal from the social involvement. This is obviously not good for any individual but it is even worse for individuals confronted with an illness such as breast cancer, which demands a great amount of motivation and initiative with regards to participating optimally in the treatment process and utilisation of resources.

According to Avis, Crawford and Manuel (2005) practical and existential aspects (for instance, careers, relationships, sexuality and finances) contributing to stressful experiences might exacerbate the stress implications of the breast cancer experience for younger women for whom such activities are of more importance than for older women.

2.2.1.4. Body image perceptions

Jade (1999) defines body image as the subjective meaning that individuals formulate about their appearance and body. It is thus not necessarily what others see that makes up a body image. According to Muth and Cash (1997), women in general report greater body image dissatisfaction and investment as compared to their male counterparts. Added to potentially existing dissatisfaction with their bodies, some women may thus have to face the physically unsettling changes brought about by breast cancer diagnosis and treatment.

Jade (1999) indicates that problems of dissatisfaction and investment in body image often manifest in negative feelings or thoughts and behaviours relating to individuals' appearance and weight and some can even develop eating disorders as a result of negative body image perceptions.

Understanding negative body image perceptions using the Self-discrepancy theory, Higgins (1997) and Lichtenthal, Cruess, Clark and Ming (2004) maintain that discrepancies between the actual self and the idealised images of the self in relation to body image, often give rise to psychological distress. The discrepancies arise as a result of psychodynamic factors and institutions such as the media and society which contribute to an individual's body image ideals and perceptions, thus determining or adding to the dissatisfaction and or level of investment that one has with ones body image (Jade, 1999; Thorne & Murray, 2000). It is therefore the level of investment in body image and the body image ideals and perceptions as conveyed through the above-mentioned institutions that interact throughout the breast cancer experience, leading women through a journey of making sense of their body image and the bodily changes whether real or perceived.

Over and above the effects that diagnosis and treatment have on body image in relation to ideals, there is also the issue of the breast as a feminine entity. In essence, both males and females have certain biological features that make them fall within a particular gender category and for women; one of those features is the breast. It forms part of sexual activity, offering stimulation and pleasure and it is also of maternal significance (breast feeding). Below is an extract from the Canadian Breast Cancer Network's 2002 report of a woman expressing her feelings on having had her breast removed:

“When you first get diagnosed, all you say is ‘take the breast off, do whatever you have to do, I want to live. ‘For me....I had to grieve for that breast. You have an altered body image” (p.1).

Another angle on body images suggested by Higgins et al. (2004) is that of the body as functional and intact. In this regard breast cancer illness and its treatment can bring about tremendous pain and side effects thus rendering an individual unable to perform tasks as they used to. With regards to functionality, the treatment of breast cancer for younger women also poses the threat of early menopause thus hindering fertility for many and this may particularly be an area of concern for younger women who have either not given birth or are still hoping to have more children.

2.2.1.5. Self-Concept

From the perspective of Social Cognitive learning theory, the self is understood to be comprised of a group of cognitive processes that individuals utilise in relating to their environment (Engler, 1999). These cognitive processes are what mark the centre of personality and also how individuals see and define themselves (self-concept). It is important to note that the self is to a large extent, a product of the socialisation process where people internalise social norms, values and identities that in a way dictate and organise appropriate and inappropriate behaviours (Monesa, 2003). The self thus comprises of the body self, cognitive self, the social self and self-esteem, which are evaluations of the self-concept (Harock & Jackson, cited in Monesa, 2003). Life experiences thus contribute both positively and negatively to the construction of the self-concept, yet on the other hand, one's self-concept also shapes experiences, thereby determining behaviour in certain situations.

Looking at cancer patients therefore, it is thus their judgement of themselves that predicts how their experience of the illness affects their self-concept. Note however, that

experiences related to or impacting on the illness are also likely to alter cancer patients' self-concepts. These experiences include factors such as "inadequate social support systems, loss of financial independence as well as advancement in the stage of the cancer" (Monesa, 2003 p. 18).

As mentioned previously that the socialisation process has a large role to play in moulding and shaping the self and ultimately the self-concept. It is thus necessary when working with cancer patients (specifically breast cancer patients in this case), to keep in mind the social constructions and definitions of womanhood as dictated by the particular individual's social norms and values. For instance, there is a biological definition of womanhood, which includes such biological features as hormones, the vagina and the breast. Linked to the biological definition and its functions is the social definition, which universally includes being a caregiver and bearer of children.

Undoubtedly, the diagnosis and treatment of breast cancer poses a threat to attempts at living up to these definitions. For instance, there exists a threat of early menopause for younger women (Gelmon, 2004) and this threatens their fertility. On the other hand, the excruciating pain brought about by the cancer, also impacts, at times, on one's ability to carry out daily tasks and activities such as child and family care and work (Baileff, 2000; White & MacLeod, 2002). The self-concept in this instance thus relates to the manner in which women's views and definition of the self (body self, social self and self-esteem) may be impacted as a result of the breast cancer experience.

2.2.2. SOCIAL SEQUELAE OF BREAST CANCER

2.2.2.1. The partner relationship and Sexuality

According to Pistrang and Barker (1995), personal relationships have a significant role to play in adapting to illness. They found a greater proportion of patients with satisfying partner helping relationships to have adjusted well to the diagnosis compared to patients with less satisfying partner relationships. The role played by personal relationships can therefore be a positive or negative one where relationships can be a source of support or stress. This largely depends on how well the couple is coping with the breast cancer (Ben-Zur, 2001; Northouse, Templin & Mood, 2001). In the midst of a breast cancer diagnosis, both practical and emotional support is needed.

A study by Maguire (1981) found that husbands of women undergoing mastectomy for breast cancer, experienced anxiety, depression and difficulty with sexual relations. Not all couples respond the same way to the breast cancer experience (Taylor- Brown, Kilpatrick, Maunsell & Dorval, 2000). Silver (2004) cites an example of some relationships taking strain that leads to the disintegration of relationships. For instance, one husband took his wife to her mother's house maintaining that he could not handle it (Silver, 2004). In the same inquiry, however, others found that the difficulty brought about by the breast cancer experience brought them closer to their partners.

Being supportive ranged from accompanying partners to consultations with physicians, to reassuring children (for those with children) that things will be better (Silver, 2004).

Aspects such as work demands and the male partner's own fears pose difficulty to the provision of support. For instance, according to Silver (2004), some partners might have to utilise their own sick leave, all in the name of being there for their partners during their time of need, while some may experience difficulty with employers who will not grant them family responsibility leave. Another important aspect as presented by Silver (2004) is that of partners being there for consultations but not knowing what to say or do and even not wanting to express their anxieties over the course of the illness, the imagined impending death and the overwhelming nature of emotions.

The aspect of body image that was discussed earlier also overlaps with intimate relationships and sexuality. According to Monesa (2003) cancer patients with altered body images may often fear and thus avoid activities that are associated with the affected body part such as the breast. Such avoided activities include dating and intimacy with sexual partners. It can be imagined that it may be more difficult for younger women who are unmarried and are still looking to initiate dating relationships as they anticipate their dating partner's reaction to the disclosure of the diagnosis and that of scars.

Silver (2004), suggests that male partners experience anxiety about physical intimacy. While they want to ensure that they maintain a certain level of physical intimacy so that the partnership stays strong and the female partner doesn't feel less attractive, there also exists confusion as to where to touch, where not to touch and whether any pain will be inflicted during sexual activity. Hence male partners might try by all means to avoid the breast area. By doing so, they might, however, run the risk of being perceived as

avoiding the breast area for the reason that it is unattractive. This may provoke guilt and shame for the partner with an altered breast and sometimes lead to her pulling away during sexual activity.

Apart from the alteration in body image that is brought about by breast cancer and its treatment, chemotherapy and surgery also have adverse side effects and these include hormonal side effects that may lead to significant changes in a woman's sexual drive and response. According to Gelmon (2004), the disruption of and or loss of sexual intimacy at a young age and at stressful times is often harder than other aspects of the treatment.

Skerret (2003) indicates that in order to optimally function in the midst of a breast cancer diagnosis, there needs to be an awareness that the difficulty is a "we" difficulty instead of one person's problem. The "we" awareness according to this author, needs to be coupled by an awareness of each partner's experience of the illness and the meaning constructed from the experience together with the building and implementing of a plan that involves the "we" (both partners) as a resource to healing.

2.2.2.2. The mother-child relationship

According to the Canadian Breast Cancer Report (2002), the following, were the words from a breast cancer patient expressing difficulty containing her children's frustration:

"I had to handle crying episodes every evening such as "I don't want you to die". At that time, I had to ask the hospital if they did not have something

written up for children, to try and explain....because I didn't know how to reassure them. You can't swear to children that you won't die... (p.2)"

According to the American Cancer Society (1993), more than 30 percent of women diagnosed with breast cancer at any time will be in their child-rearing years. With the diagnosis of breast cancer in younger women, there instantly arises a need for adjustment within the household, including the parent-child relationship.

The parent-child relationship is a significant one in the accomplishment of life's developmental tasks as well as in the child's general functioning. The condition of an ill parent, who has to be in and out of the doctor's rooms, is in pain and has impaired energy levels, might therefore be detrimental to the parent-child relationship and the child's functioning.

The mother may be emotionally drained and thus emotionally inaccessible. She may also be depressed and fatigued. This may yield impairment in parenting skills, which may impact on children's self-esteem as well as the development of social and behavioural problems because of the poor quality of the parent-child relationship (Lewis, Hammond & Woods, 1992). Amongst the emotions likely to be experienced by breast cancer patients, Champagne (2003) identifies guilt including being a mother but not being able to fully take childcare responsibility.

An area worth looking at in relation to parent-child relationships at the time of breast cancer diagnosis is that of the child's age and developmental stage and also that of the experience of single mothers who might not have a partner to provide a parental figure. However, there is a paucity of literature in this regard.

2.2.2.3. Social Networks: Friendships and extended families

Colville (2005) defines social networks as "A series of formal and informal ties between the central actor and other actors in a circle of acquaintances" (p. 1). Within these social networks exists the concept of social support, which includes both a practical and emotional form of support as offered by people within one's social network. According to Garbarino (1983), a social support network is therefore a relationship characterised by interconnectedness, which offers invaluable patterns of interaction, interpersonal relations, nurturing and reinforcement for daily coping and functioning and much more so during testing times thus helping individuals regain their physical and psychological health.

Bolger, Foster, Vinokur and Ng (1996) see social support networks as a source of assistance during stressful times such as breast cancer and also as mediators of better adjustment through the provision of practical and emotional support. These authors further pose two questions whose answers hold critical to the effectiveness of social support networks. Firstly, is the social support network sensitive to the distressed person's cry for help enough to provide support? Secondly, are the distressed person's needs met by the support provided?

As much as most would like for their social networks to be supportive, it is worth noting, however, that some factors may undermine the provision and effectiveness of the support thus resulting in individuals not receiving the support they expect and deserve. For instance, Bolger et al. (1996) suggest that overwhelming chronic exposure to a cancer patient's difficulties and distress can at times exhaust the individuals' social networks thus robbing the patient of the expected and deserved support.

2.3. Theoretical Framework

The current study is located within the biopsychosocial approach to illness. With its basis on general systems theory, Engel developed the biopsychosocial model in 1980, seeking to move away from the reductionist approach to health and illness that was evident in the biomedical model (Van Niekerk & Prins, 2001). The biomedical model basically assumes a single causality for ill health, and that is disease. The biopsychosocial model on the other hand recognises much more than the biological basis of ill health by adding psychological and social factors as influential in the onset, manifestation and course of ill health.

Kleinman (1977) distinguished the two concepts by maintaining that disease refers to the body's malfunctioning thereby making disease the description that the doctor would give the patient while illness would constitute of the patient's perspective (lived experience) of the disease. For instance, a doctor may firmly believe that one is presenting with signs and symptoms of tuberculosis while the patient strongly believes that a jealous neighbour

or family member has bewitched him/her. For optimum treatment adherence and cooperation, it would be important that doctor and patient engage in a process of illness negotiation to account for each other's explanatory model (Swartz, 1998).

According to Lo Castro (2003), the biopsychosocial approach maintains an interwoven relationship between biological, social and psychological factors. This relationship between the biological, social and psychological factors thus sees these factors interacting in affecting and influencing health and illness. Practitioners adapting the biopsychosocial model therefore acknowledge that there exist connections between the biological, mental and psychological facets of health and illness. This understanding is also in line with the World Health Organisation's definition of health as not only referring to the absence of disease but a state whereby there is complete physical, mental and social well being (Wissing, 1999).

Looking at the study at hand, there is recognition that while breast cancer as a disease is a physiological process, as an illness it is also a psychological and social process as it involves such experiences as depression, anxiety and strain on intimate and parent- child relations. Only focusing attention on the physiological aspects would be inadequate.

Furthermore, Schlebusch (1990), also maintains that although illness occurs within each individual, it does however, occur as part of a larger system. In the context of the research at hand the concept 'system' can be seen as composed of aspects such as cells,

body organs (biological factors), family, society and mental well being. Justification for utilising the biopsychosocial approach to illness is summed up quite well by Kroenke (2006) in the following quotation:

“We need to triangulate the “bio”, “psycho” and “social” aspects of illness to provide optimal, patient centred care”. An overly narrow view results in myopic science as well as practice (p.1).”

Van Niekerk and Prins (2001) present Winiarski’s extension of the biopsychosocial model which goes to include the spiritual realm, recognising that human beings have spiritual qualities as well that mediate, direct behaviour and are sometimes referred to for guidance and in search of peace and calm.

2.3.1. Erikson’s Epigenetic Principle as a Complimenting Theoretical Framework

The current study focuses on a specific age group, which is why the researcher found it appropriate to utilise Erik Erikson’s work on developmental stages (epigenetic principle) in order to put into context the identified group’s experiences with breast cancer in relation to their chronological developmental stage. Erikson developed a human development theory that not only focuses on childhood but also extends throughout adulthood into old age. In his human development theory, Erik Erikson held strongly that development in life unfolds in stages and that these stages have tasks or crises that need to be resolved. Failure to achieve mastery on these tasks thus sees a disturbance in the

development process (in the subsequent stages) as witnessed through physical, cognitive, social and or emotional maladjustment (Kaplan & Sadock, 2003).

Erikson divided the human development process into eight stages as labelled with the conflict or task that has to be resolved in that stage:

- 1 Trust vs. mistrust
- 2 Autonomy vs. shame
- 3 Initiative vs. guilt
- 4 Industry vs. inferiority
- 5 Identity vs. role confusion
- 6 Intimacy vs. isolation
- 7 Generativity vs. stagnation
- 8 Integrity vs. despair

The age group (21 and 40) that was targeted by the current study falls within the sixth stage (Kaplan & Sadock, 2003 &, Van Niekerk & Prins 2001). During this stage, individuals are faced with tasks relating to affirming their identity, finding out what matters most to them (values), establishing a career, developing intimate partner relationships and establishing a family (Van Niekerk & Prins 2001). These tasks need to be mastered without necessarily impairing ones ability to love or to work (Kaplan & Sadock, 2003). Failure to master the tasks in this stage is highly likely to result in isolation as opposed to intimacy.

The epigenetic principle of human development gives an excellent framework for understanding individuals in relation to the developmental tasks that they are confronted with at any given time. For instance, the literature review highlighted possible difficulties with intimate partner and child-parent relationships emerging as a result of breast cancer and Erikson's development theory highlights how for the target population of this study establishing intimate and family relations are important developmental tasks.

2.4. CONCLUSION

There is a fair amount of literature on understanding the trends of breast cancer prevalence; understanding the illness as a biological phenomenon as well as understanding the challenges it imposes on psychological and social functioning. The process unfolds in stages that demand that individuals engage in information gathering and the utilisation of resources of all forms. For instance, information and awareness on the nature of breast cancer might not be present at the time of diagnosis, let alone information on treatment options and their side effects. The process evidently places enormous pressure on psychosocial functioning and with the heightened prevalence of HIV/AIDS, single motherhood and unemployment among women in South Africa (especially those of African descent), it is thus evident that those affected by breast cancer face a variety of challenges that can disrupt what is often termed normal functioning. This study therefore aimed at developing an understanding of the experiences of younger women with regards to the psychosocial effects of a breast cancer diagnosis thereby assisting the health profession in intervening at the social and

psychological levels of functioning to facilitate more holistic and client centred interventions for younger women with breast cancer.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1. Introduction

This chapter outlines how the research process unfolded and how the researcher strived to access rich and valuable knowledge from the participants. Mohamed-Patel (2002) stresses that it is essential for researchers within the social sciences and psychology to study subjective meanings and everyday life experiences in order to understand the unique nature of certain phenomena. Quantitative methods have constantly been under criticism when it comes to their efficiency in explicating such everyday life experiences (Morse, 1997). In light of the current study's aims which are to understand the psychosocial experiences unique to younger women in relation to breast cancer diagnosis and treatment, a qualitative approach was appropriate and thus selected for use. In particular the current study employed a case study methodology.

3.2. Aim and Research Questions

Aim

The study aimed to develop an understanding of younger women's experiences of breast cancer as shared in relation to diagnosis, treatment and beyond.

Research Questions

The study sought to answer to the following questions:

- What are the psychosocial impact of breast cancer diagnosis and treatment?

- How are these psychosocial experiences unique in younger women?

3.2. Case Study Approach

Yin (2003) defines a case study as an “empirical inquiry that investigates a contemporary phenomenon within its real life context, especially when the boundaries between the phenomenon and the context are not clearly evident” (p 13). In simpler terms, the case study methodology is used when the researcher believes that contextual factors and the phenomenon under investigation have the potential to influence each other. The case study approach was deemed appropriate for the study at hand as the literature review section demonstrates that the experience of illness, and more specifically breast cancer in this instance, is influenced by contextual psychosocial factors.

Further, Feagin, Orum and Sjoberg (1991) assert that a case study approach is ideal for researchers attempting to carry out a holistic and in-depth investigation. This study is concerned with developing an in-depth understanding of the psychosocial experience of breast cancer diagnosis and treatment in younger women.

According to Tellis (1997) through the use of case studies, the viewpoints of the participant are brought out. Tellis (1997) further asserts that in an attempt to bring out these details, the case study approach considers the voice and perspective of the concerned group of participants as well as the interaction between them. Utilising case study methodology thus saw the selection of a few examples of the phenomenon under investigation and the intense exploration of the characteristics of those examples or cases.

The selection of a few cases allowed the researcher the opportunity to closely examine, compare and contrast the few chosen cases. This allowed her to become familiar with specific and significant features of the experience of the diagnosis and treatment of breast cancer in younger women, learning in the process, how the phenomenon varies when subjected to different contexts and situations.

There are different types of case studies namely, exploratory, explanatory and descriptive case studies. According to Yin (2003, p. 5) the following factors need to be considered when selecting a strategy in case studies:

- (i) Type of research questions asked.
- (ii) Extent of control an investigator has over actual behavioural events.
- (iii) The degree of focus on contemporary as opposed to historical events.

The explanatory case study was selected for use in the current study as, according to Yin (2003) it seeks to answer how and why questions that are not only inquiring into incidence but also into experiences over a certain period of time. The explanatory case study was deemed fit for the current study as it sought to understand how the participants experienced the diagnosis and treatment of breast cancer from a psychosocial perspective, as well as attempt to understand why they experienced it the way they did given differing contextual considerations.

The current study adopted a multiple case study form as opposed to a single case study. Multiple case studies are reported to be more powerful than single case studies because evidence from multiple sources is more compelling and robust (Herriott & Firestone, 1983; Yin, 2003). Further, each case contributes to the prediction of similar or contrasting results but for reasons that are predictable (Yin, 2003).

The selection of five cases in this study is supported by Yin (2003) who asserts that between 4-6 cases is appropriate for studies aimed at developing an understanding of issues at hand through the use of a theoretical framework as it applies to the study. Such a number of cases allow the researcher the opportunity to engage deeply with their findings, with inferences and conclusions being made with the theoretical framework being a point of reference. This is much more so in the study at hand, as the researcher drew much of her understanding from the biopsychosocial model and the epigenetic principle as theoretical frameworks informing the study. The use of these theoretical frameworks was made in an attempt to understand the breast cancer experience in context.

3.3 Data Collection Method

Tellis (1997) asserts that interviews are one of the most vital sources of information in case studies. Interviews can take different forms from structured to unstructured. The semi-structured interview was selected for use in this study. Barribali and While (1994) assert that this type of interview provides rich yet spontaneous information as the

researcher is able to explore pre-determined issues, through the use of a semi-structured interview schedule, while simultaneously allowing for participants to elaborate on issues.

An advantage of the semi-structured interview is that it also allows the researcher the opportunity to observe participants' non-verbal presentation and attitudes so as to better assess information given and to probe further into certain gestures and expressions. As mentioned in the introductory chapter, the aim of the study was that of gaining insight into the experiences of breast cancer diagnosis and treatment in younger women from a psycho-social perspective. In line with the aim of the study, an interview schedule was therefore developed after a thorough review of the literature on issues usually of concern to breast cancer patients, with experiences of younger women being at the forefront. Also in line with the theoretical framework employed in this study, the areas explored in the interviews centred on issues relevant to the illness experience and its impact on psychological and social well being. Most importantly though, the interview schedule aimed to elicit rich understandings of how these experiences would be unique for women of younger age in relation to their developmental stage in the life cycle, when compared to the often researched older women. The interview schedule utilised in the study thus sought to tap into the following factors of psychological and social concern in relation to the diagnosis and treatment of breast cancer as well as developmentally appropriate tasks as can be seen in the inclusion of the mother-child relationship since child bearing and rearing is still a developmentally significant activity at this stage.

(i) Psychological Factors

- 1 Depression
- 2 Anxiety
- 3 Stress
- 4 Body-Image Perceptions
- 5 Self-Concept

(ii) Social Factors

- 1 The partner relationship and sexuality
- 2 Social Networks: friendships and extended families
- 3 The mother-child Relationship

A copy of the interview schedule can be found in appendix B.

3.5. Data Storage Methods

The interviews were conducted in the Zulu language, as this was a common language between the researcher and participants. The interviews were also recorded, each on a separate cassette, with the permission of each participant. The interview sessions took approximately 45 to 60 minutes in duration. Each interview was then assigned a code, which was also utilised as a label for the corresponding cassette. An example of such a label is as follows: **Participant A, 02 October 2006**, which refers to the first participant who was interviewed on the 02nd of October 2006. Each audiotape was listened to and

transcribed shortly after the interview. Translation from Zulu took place during the transcription process.

These audiotapes and transcripts were filed safely to be destroyed after the examination process of the dissertation had been completed. Observational notes were also made during interviews and these were filed attached to each transcript.

3.6. Participants

Participants were selected through volunteer purposive sampling, which Kruger (1988) regards as the search for those “who have had experiences relating to the phenomenon to be researched” (p. 150). Guided by this technique, the researcher approached officials at the Cancer Association of South Africa in Pietermaritzburg, informed them about the study and requested them to pass the information through to their breast cancer patients falling within the target age group. The officials were requested to inform potential participants about the purpose of the study as well as to encourage them to partake in the study, emphasising in the process, the voluntary nature of their participation.

An outline of the participants’ profiles is as follows:

3.6.1. Description of Participants

Below follows brief descriptions of participants in the current study. These descriptions are aimed at introducing the reader to each participant and their background so as to

better relate findings outlined in the subsequent chapter to participants' contexts. A crucial point of note is that all the participants came from affluent urban backgrounds, with four of them having tertiary qualifications while only one had a matric level education.

1. Participant A, 02 October 2006

This participant was aged 40 at the time of interviewing and was first diagnosed at the age of 25 (1991) and had a recurrence five years later (1996). She discovered the cancer after a health campaign for learners at a school where she used to teach. Participant A was born into a large family where she is a first-born and was a breadwinner for a long time. Being a breadwinner evoked a lot of difficulty in this participant's life during the breast cancer experience as there arose concerns over the possibility of her losing her job or dying thus leaving her family in poverty.

At the time of diagnosis and treatment, Participant A was not married but had a partner who lived and worked in Johannesburg, while the participant lived and worked in Pietermaritzburg. She reported this partner as having been supportive throughout the experience, despite being far from her. Participant A also reported that her partner was however, preoccupied with the possibility of losing her to the cancer. This partner however, passed away during a shooting, shortly after she completed her first round of treatment. She then later met someone who she reported was also very supportive and with whom she only parted after deciding to follow her calling of being a 'born again' Christian.

Participant A has since gotten married and reports that her husband has stood by her through thick and thin despite the complications brought about by the cancer experience. This participant reported difficulties with her job during the treatment process and these difficulties, she reports, led to her being instructed to sign up for grant payment due medical condition and leave her job. These difficulties included constant difficulty reporting for work and difficulty carrying out her duties once she got to work (lifting up her arms to write on the board). She also reported difficulty with her superiors as they did not fully understand her condition and that it could be healed. She did not however, experience any difficulty with finances for seeing to medical procedures as she was on medical aid and it did not run out.

Participant A maintains that during the breast cancer experience, she became born again and had a calling to start a church and is now a pastor, and despite being presented with the opportunity to go back to teaching, she refused the opportunity and does not dream of going back to teaching as she is now devoted to her religious work. Participant A currently has no biological children, but has two daughters and a son who she adopted after they had been orphaned. Participant A is a very religious (Christian) person who has adopted religion in understanding her illness as well as her source of strength. Participant A had her whole breast removed and underwent both radiotherapy and chemotherapy. She travelled to Durban for her radiotherapy sessions.

2. Participant B, 19 October 2006

This participant was diagnosed in March 2006 at the age of 38. She found out that she had breast cancer because of a pain in her armpit, which had persisted despite taking painkillers to remedy the pain. At the time of interviewing, she had already finished her chemotherapy treatment but was still going for radiotherapy treatment. Participant B is a teacher by profession. She teaches mainly grade 12. She reported having forced herself to go to work as she worried about the negative impact that her absence and the changing of teachers every now and then would have on her grade 12 learners.

Participant B is married with three children, aged ten, eight and four and is still uncertain as to whether she would like to have more children. She is however, aware and saddened by the potential limitations that treatment might have had on her fertility should she and her husband decide to conceive again. This participant reported a history of breast cancer from her maternal side of the family (maternal grandmother). This history of breast cancer was said to have never been talked about as it evoked bad memories for the participant's mother who lost her own mother to breast cancer at a very early age.

This participant also reported multiple deaths in her family, with her brother and sister having passed on after long illness, one after the other, within a very short space of time. The participant's husband was also reported to be a supportive partner who is however, non-expressive, especially when it came to the sexual problems experienced by the couple at some point during the treatment. Participant B drew a lot of support from the people that she goes to church with. She also reported being highly religious (Christian).

Participant B's children were reported to have been shocked, confused and saddened by their mother's diagnosis. However, this participant reported that showing her children the affected breast, allowing them to touch it, talking to them about the cancer, explaining to them everything that was happening and what they could expect, demystified the cancer in the eyes of her children. Participant B had only the tumour in her breast removed and not the whole breast, as the cancer was still in its early stages.

3. Participant C, 22 October 2006

Participant C was diagnosed in 1998 at the age of 32 and was aged 40 at the time of interviewing. What led her to finding out about the cancer was the pain she felt in her left arm, which prompted her to consult with her practitioner. She was already married at the time of diagnosis, had two children, one aged five and one aged 13. Soon after being diagnosed, the participant received news that she was also pregnant and that the baby would have to be delivered prematurely, so that she could soon start with breast cancer treatment.

At the time of diagnosis and treatment, she was working in a flower shop and was getting paid on a wage basis. The participant reported having had a difficult time striking a balance between the treatment process as well as consistency in her work. Despite her employers not firing her from her job, Participant C reported having sensed tensions amongst her employers at those times when she had to request time off or was not feeling well enough to carry out her tasks. She is currently employed as a general administrative

assistant by a governmental department. This participant is her mother's only biological child and was taken into another marriage where she grew up with half brothers and sisters. She reported that it had not been easy growing up with half brothers hence she spent most of her time at her maternal grandmother's house as a child.

Participant C's mother was reported to have played a highly supportive role when the participant was diagnosed and was going for treatment, especially at times when the participant went for chemotherapy sessions as she would not be able to do anything, let alone move, after her chemotherapy sessions. Her mother as well as her friends and neighbours would take turns helping out with house chores. The participant's husband also provided her with great support of all forms and she believes that he was even more sensitised to her condition because of his work in the Department of Health. Participant C had her whole breast removed and underwent both radiotherapy and chemotherapy.

4. Participant D, 27 October 2006

Participant D was diagnosed with breast cancer at the age of 31 after she had had a lump under her arm for 3 years without taking it seriously since it had not been painful. In June 2005, she started feeling a pain in her left breast and that was when she consulted, had examinations done and was diagnosed with breast cancer. Of the interviewed participants, Participant D was the only one who mentioned that she had received pre-counselling before receiving the diagnosis. Participant D was not married at the time of diagnosis and treatment and is still unmarried.

However, at the time of diagnosis, she was engaged to be married and shared a home with her fiancé who was said to have been a supportive partner, supporting her in every way including taking care of the participant's adoptive child. She has never had children but adopted her sister's daughter after her sister passed away while the child was seven months old. The participant's partner passed away in April 2005 and at this time she started having intense side effects which she suspects might have been linked to the pain of losing her partner. Before losing her fiancé, the participant had also lost her sister and mother.

Following losing her partner, the participant took six months worth of leave and relocated to Johannesburg to live with her sister and was still on leave at the time of interviewing in Johannesburg. Despite an awareness of the potential impact of treatment on fertility, Participant D still longs to have children of her own, despite being currently single. This participant currently has as her family, her father who lives in a different province, her brother, as well as her nieces and nephews. She reports having found a lot of strength and support from her sister, her brother who lives in Pretoria as well as the people she goes to church with, as she is religious (Christian). Participant D is employed as an artisan by the Department of Correctional Services and had just finalised a transfer to Johannesburg at the time of interviewing. This participant had both her breasts removed and underwent both radiotherapy and chemotherapy.

5. Participant E, 10 December 2006

Participant E is a married 31-year-old nurse who was diagnosed with breast cancer in June 2006 and was still undergoing treatment at the time of interviewing. She currently has one child who stays with her mother since the participant works away from home. Participant E is one of three children in her family, one of whom passed away in 2004 thus leaving her as the breadwinner for her maiden family. She is also the only daughter. This participant had her whole breast removed as part of the procedure and currently uses prosthesis. Participant E is married but does not live with her husband as they both work in different towns. She also did mention that her marriage was going through a difficult time before diagnosis and that the breast cancer experience had not made things any easier for her marriage.

3.5. Ethical Issues

Prior to commencing with the study, ethical clearance from the University Ethics Committee was obtained. Secondly, the researcher found it crucial that officials liaising with breast cancer patients and survivors ensured that potential participants were informed of the voluntary nature of their participation in the study. Furthermore, prior to each interview, the researcher explained the informed consent form to participants. The consent form (see Appendix A for a copy of the form) covered the purpose and nature of the study as well as the following ethical issues:

1. Voluntary nature of the research
2. Willingness and fitness to participate
3. The value of the information to be gathered

4. Procedures of the research
5. That participants could stop the interview at any stage should they find themselves feeling uncomfortable
6. The avoidance of any harm to participants
7. Anonymity

The Cancer Association of South Africa gave the names and contact details of potential participants to the researcher after they had spoken to them first. The researcher then contacted potential participants to arrange interview times as per participant's availability. The choice of the venue for the interview was also reached upon inquiring into places that participants would be comfortable with. Four of the participants were interviewed in their homes, while one was interviewed at the researcher's place of work, shortly after working hours. Participants were given diaries as a token of appreciation for their participation and the gifts were funded by the researcher's personal funds.

In total, 5 individuals falling within the targeted age range 21 to 40 participated in the study. All the participants were of African descent and this was due to accessibility rather than selection on the basis of racial background. Four of the participants were from in and around the Pietermaritzburg area while one was based in Johannesburg at the time of interviewing, following relocation. They had all been diagnosed and treated for breast cancer.

3.7. Data Analysis

The data was analysed thematically, based on the understanding gained from Boyatzis' (1998) work on thematic analysis.

3.7.1. Thematic Analysis

The core activity of the research process is that of the analysis of data, which follows after the researcher has gathered information from informants. A variety of approaches exist from which the researcher can choose to analyse knowledge imparted by informants. Thematic analysis is one of these various analytic approaches and was selected for use in the current study. Braun and Clark (2006) assert that thematic analysis is indeed a basic analytic method which thus renders it suitable for qualitative researchers starting out in the field of research as it helps in the development of their research abilities lest there arise a need to use other forms of analytic methods in future.

Braun and Clark (2006) describe thematic analysis as an analytic approach that is used in the identification, analysis and reporting of occurring patterns within data. According to Boyatzis (1998), thematic analysis is an excellent way of transforming qualitative data as it enables researchers to utilise various sources or types of information thus increasing their accuracy and sensitivity in comprehending and explaining observations about people, events and situations.

In an attempt to relay knowledge that is rich and that would otherwise not be evident to others, the current researcher utilised thematic analysis to track patterns from the data gathered through interviews. Patterns ranged from significant events to emotionally

significant moments. Recognising patterns marks the most basic of steps to thematic analysis. The identification of themes using thematic analysis was followed by the process of labelling or coding, giving definitions or descriptions to the identified patterns. The labels given to patterns are known as themes. Boyatzis (1998) defines a theme as “A pattern found in the information that at minimum describes and organises the possible observations and at maximum interprets aspects of the phenomenon” (p.4).

An example of a theme in the current study would be that of the subheadings “depression” or “the mother-child relationship” which aimed at grouping patterned experiences that emerged from the results in relation to depressed mood and the relationship between mothers and their children. Within the stage of developing themes lies three ways of achieving this process. Boyatzis (1998: p. 29) outlines these three ways as follows:

- (i) Theory driven analysis.
- (ii) Prior data or prior research driven thematic analysis.
- (iii) Inductive thematic analysis/ data driven.

The current study employed both a literature and theory driven approach to thematic analysis. The collection and analysis of literature assisted the researcher in identifying essential areas in the breast cancer experience as well as identifying gaps in research. Boyatzis (1998) defines the theory driven approach as one where “Insight can be derived from application of the model to a set of information, whether through hypothesis testing

or through searching for consistencies or anomalies” (p. 30). Despite the theory driven approach to thematic analysis having an underlying assumption that there are always laws and principles to be applied to phenomena (Diesing, 1971), the current researcher took extra care to not completely superimpose theory on the knowledge obtained and ignore other possibilities and or dynamics related to context.

It is worth noting that thematic analysis in the current study was not only used at the analytic stage of the research process but was also used at the beginning of the inquiry. Such use of thematic analysis is in line with Boyatzis’ (1998) recommendation that the use of thematic analysis can prove worthy when applied while formulating the research agenda, enabling the researcher to gain access to a variety of information. Identifying patterns alone and compressing them into a narrative of collective experiences does not enlighten the reader about the topic under study. That is why it is imperative that the researcher reads related literature in order to be able to construct a valid argument that supports how the themes came into being. Formulation was thus the last step in thematic analysis in the current study (formulation is when literature blends with the findings and follows in chapter five). This last step allowed the researcher to develop and present a meaningful story line thus helping the reader to understand the process as well as the researcher’s and informants’ point of view and is contained in chapter 5.

3.8. Reliability and Validity Checks

In all research, careful consideration needs to be given to reliability and validity and this is much more so in research where the recording, transcription and translation of conversation has taken place because data collected in this manner is likely to get altered along the process. Reliability and validity thus aims to ensure that the study is of quality and thus worthy of being given attention. According to Patton (2001), validity and reliability are two factors that the researcher should be concerned with during design and analysis. Thus various measures of reliability and validity were implemented in order to ensure quality in the current study.

3.8.1. Reliability

Reliability seeks to answer questions relating to whether the manner in which the study has been conducted is stable and consistent to such an extent that it would yield similar results if the same study were to be carried out again, under similar conditions.

According to Yin (2003), the aim of reliability is to ensure that errors and biases are minimized. The aforementioned author further recommends that researchers document the procedures followed in their studies so that future researchers following up on earlier studies be allowed to repeat similar investigations.

The researcher of the current topic took a hint from Yin's (2003) suggestion that one makes steps in the research process as operational as possible and conducts the study as though someone were always keeping watch over them. This allowed the researcher's supervisor to be able to read and keep track of the proceedings and righteousness of the

research process. This will also allow researchers intending to carry out research along the same lines, the opportunity to refer to the current study.

3.8.2. Validity

Validity is concerned with answering the question of whether a particular study and its operations are indeed tapping into what the study was initially set out to, so as to ensure that chances of making incorrect inferences are reduced. In qualitative research, validity can be ensured through the use of such techniques as triangulation, member checks and peer review. Triangulation in this instance refers to the use of a combination of multiple means of accessing information, such as: using different researchers or evaluators, sources of data, methods (for example interviews and surveys) as well as looking at the same phenomenon from various theoretical positions (Neuman, 2000). Member checks on the other hand are concerned with the researcher, taking the findings back to the participants for their verification. Since validity is concerned with whether the study's findings do reflect the truth certain techniques as outlined below were employed to ensure the truthfulness of the study.

3.8.2.1. Internal Validity

The current study utilised internal validity which according to Yin (2003) can be achieved through the matching of patterns and building of explanations where rival explanations are also addressed. This can be achieved through using the selected theoretical construct as a benchmark. Drawing from techniques within internal validity, the researcher in the current study utilised peer review as a technique for ensuring the

data were indeed relevant to what the study sought to achieve. Merriam (2002, p. 26) defines a peer review as involving “asking a colleague to scan some of the raw data and assessing whether the findings are plausible based on the data”. A colleague familiar with the field of psychology was requested to play the role of peer examiner for the current study. The examination of the final report was also a means of achieving internal validity for the study at hand, where different evaluators examined the final report of the current study.

3.8.2.2 External Validity or generalisability

In addition to internal validity, an attempt at ensuring external validity was also made in the current study. In essence, external validity is concerned with whether the results of a study can be generalised to other more or less similar situations. According to Merriam (2002), statistical generalisation is not feasible in qualitative studies as the selection of small non-random samples does not necessarily prove representative of populations. However, the act of detailing sufficient, rich and contextually relevant findings of the current study has been done with the aim of assisting those who might refer to the study thus enabling them to read and understand the findings and determine whether any of the findings can be generalised in any way to their situations.

CHAPTER 4

RESULTS

Introduction

This chapter focuses on outlining the themes that emerged from thematic analysis of the data obtained from the semi-structured interviews held with the participants, as outlined in chapter three. In addition to themes based on the semi-structured interview, themes that spontaneously emerged during the interviews and were common among participants, despite being absent in the interview schedule are also reported on. These themes are as follows:

4.1. PSYCHOLOGICAL IMPACT

(I) Depressed mood

There were reports on the emergence of depressed mood amongst all participants following diagnosis. Depressed mood was not only experienced by the participants, but by those close to them as well. The common features were feelings of sadness, tearfulness as well as the question, “why me”. Reasons for feeling depressed varied

across participants and this variation clearly demonstrated the role that the uniqueness of each individual's context and situation plays in influencing their experience of illness. The reasons for experiences of depressed mood are reported below as sub-themes.

- **Thoughts about death:**

Accounts from three of the five participants illustrated that there had been experiences of depressed states as a result of an anticipated loss of life due to breast cancer. It also emerged however, that not only participants experienced depression in relation to thoughts about death, but their loved ones were also significantly saddened by these thoughts. Being a breadwinner at home or having experienced a loss prior to diagnosis marked the core of the reasons that evoked depressed states when anticipating death. Examples of participant's accounts of their experience of depression during the breast cancer experience are outlined in the extracts below.

For one of the three participants that reported depressed mood due to anticipation of death, the participant's death would have marked implications beyond a loss of life.

Participant A, 02 October 2006 was aged 25 at the time of diagnosis. She was single and had no children. She is a teacher by profession despite having left the profession due to illness. She is the firstborn amongst her siblings and at the time of diagnosis, she was the only person in her household with a tertiary qualification as well as a stable source of income. Her parents had reached the late adulthood stage in their lives hence she was the

breadwinner. It had hardly been a year since she had started working when she was diagnosed with breast cancer. Her cancer was aggressive and was later recurrent too. This proved extremely life threatening as well as consequently threatening to hers and her family's financial standing. Being faced with breast cancer at that time, anticipating her own cessation from existence and the threat it imposed on her ability to provide for her family, made her see herself as weak and vulnerable, sinking her deep into depressed mood. Below is a quotation illustrating this participant's experience.

"I was sad, thought I was going to die. I was worried about not being able to take achieve my dreams and help my family out" (Participant A, 02 October 2006).

Apart from the above participant who experienced depressed mood as a result of looking at the implication that her death would have for her family's survival, it also emerged that for families of two other participants in the study, thoughts about death and the resulting onset of depressed mood were underpinned by prior experiences of loss. In these participants' families, there had been losses of loved ones through death after long illness. These losses at times occurred in succession and also not so long before both participants' diagnosis. Participant's illness from breast cancer was therefore viewed by their loved ones as an experience that was bound to soon sustain the death pattern in the family. Families thus found themselves engaging in recollections of the loss experience as well as imaginings of the pain of losing yet another loved one.

“All in all, I would say that my family did not receive it very well, they became very worried, especially my mother as she felt she knew what the diagnosis meant. And she started recollecting, recalling that my other sister and brother had died and left their very young kids and this meant I was also going to die and leave my kids at such a tender age. She just saw the cancer as coming to sustain the pattern. To her it meant that I was going to die just like her mother had died of cancer and there was also this pattern that was taking place. I think my mother was the most affected by the diagnosis. She was sad and cried all the time. It slowly destroyed her inside” (Participant B, 19 October 2006).

My mother also thought I was going to die when she heard of my diagnosis and she was very sad. My brother would call me at times and tell me she was crying and was not eating well but it eventually sank that breast cancer can be treated and she is coping now.” (Participant, E, 10 December 2006).

It therefore seemed that family members of these two participants experienced significant levels of depressed mood.

- **Physical difficulty and inability to actively sustain families:**

One participant, in particular, reported feeling particularly distressed about not being able to actively take care of herself and her family. The most crucial factor to note at this point was that this participant had had to have her child delivered prematurely in order to start on treatment as her cancer was aggressive. This therefore did not give her adequate time

to care for her new born as she would have loved to. It had also been a short while since getting married when she was diagnosed and it distressed her that she was unable to provide the nurturance to her husband and children that she was committed to providing.

“I felt really sad and like I was not so much of use when I was not able to bathe myself, not able to look after my children, especially the new born, or cater for my husband, after the third session of chemo. At times I would just sit there and cry because I could not do anything else anyway, just could not move” (Participant C, 22 October 2006).

- **Possibility of not being able to bear children:**

Of the interviewed participants, only two did not have children and of the two, only one was not married. The one unmarried participant was concerned that she may never be able to bear children and that made her particularly depressed. At the time when she was diagnosed, she was engaged to be married, however, her partner passed away during the treatment process. Before diagnosis, the couple was reported to have been making attempts at conceiving and these were evidently unsuccessful. It is believed that having lost a partner who was there when the ordeal started, being currently single as well as having undergone intense treatment procedures are among some of the factors that contributed to the participant’s distress over the possibility of her not being able to bear children in future. Her partner may have easily been able to understand what caused the inability, it may still take her some time to be involved again and the treatment has

indeed posed a threat to her fertility. This is how Participant D, 27 October 2007, expressed her feelings over the situation.

“No, I have never had children. Sad though, because my fiancé and I were trying to conceive when I was diagnosed. When I received the diagnosis and started treatment, my doctor advised us to wait at least three years after treatment and now my fiancé is gone. And I guess if I do find myself in another relationship it might take some time to have children or it will just never happen. I am very aware of that and I must say in a way it does feel like one of my dreams may never come true... (Starts sobbing)...I am okay, we can continue” (Participant D, 27 October 2007).

(ii) Anxiety

Four out of the five participants in the current study reported having experienced anxiety. Similar to depressive mood, reasons for anxiety also varied across participants and this variation yet again emphasised the need to pay careful consideration to context. Over and above context, this variation also served to highlight how phases of the breast cancer experience can tend to evoke psychological reactions relative to particular phases. Reasons for feelings of anxiety are reported as sub-themes below:

- **Anxiety upon receiving the diagnosis:**

All participants reported that their most immediate reaction as well as that of their loved ones after receiving the diagnosis was one of shock. However, three participants went on to further report that loved ones' shock was soon followed by anxiety over the likely

course that the illness would take. It seems what then became critical at this stage was for participants to contain loved one's anxieties and attempt to provide them with answers and reassurance while they themselves may have had their own anxieties and concerns. In this way, participants' own anxieties may have been put aside, leaving them not dealt with. This need to contain other people's anxieties was the case for three participants in particular. These participant's experiences are captured in the following excerpts:

Participant C, 22 October 2006 had two children at the time she went for treatment, one a few weeks old and one aged 13. She was married and thus lived with her husband and two children. She came across as being very loving, nurturing and thus involved with her family. Below is a quote illustrating her son's anxiety over the likely course that the illness may take and what it may mean for him and his father.

“ The first born is a boy, and was thirteen at that time and although he did not understand everything about the illness, he was quite clear on the fact that I was not feeling well and that it could get worse. I mean he is a boy so he did not really express how he felt that often but it still came across clearly that he was saddened by this and did at times ask what would happen if it got worse and what would him and his father do without me. I just had to keep assuring him that I was going to be okay even though I was not so sure and was worried myself” (Participant C, 22 October 2006).

What is strikingly apparent in the quotation above is that given the participant's role as a mother, she had to contain other's anxieties about what her condition meant for them even in the face of her own anxieties.

Participant E, 10 December 2006 had a younger brother who at some point during the illness experience, expressed his anxiety in the following words. This participant had lost her older brother before diagnosis and was thus the only sibling that her younger brother had.

"My younger brother still asks me whether I am no longer going to die since I have had my breast removed. I think the experience of losing our older brother is still very painful to him and he cannot handle the thought of losing me as well" (Participant E, 10 December 2006).

Having just started out on a stable career, Participant A, 02 October 2006, had major plans set for her family and her life in general. These plans included the life she had built and was still planning to build further with her long distance boyfriend. Her boyfriend was said to have been very supportive but also had constant anxieties over his partner's potential failure to survive the breast cancer. Below is a quote relaying the participant's experience of her partner's anxious feelings:

"In 1991 when I was first diagnosed, I had a boyfriend.....He was really worried shame....., he thought I was going to die, He was in Johannesburg and he called

everyday when I was in King Edward. He would ask what the doctors were saying about my condition because he thought I was going to die anytime” (Participant A, 02 October 2006).

- **Anxiety before commencing treatment and or during treatment**

Three of the participants in the current study reported being anxious about the side effects of the treatment process. Participant B, 19 October 2006 was preoccupied about the side effects before the treatment as a result of what she had read or heard about. Meanwhile, Participants C, 22 October 2006 and Participant, E 10 December 2006 had their anxieties evoked by exposure to the treatment and thus prior experiences of the side effects.

Participants mentioned, in particular, anxiety over the temporary physically disabling nature of treatment, hair loss and nausea as a result of chemotherapy. Below are excerpts capturing participant’s anxieties over side effects.

“Oh yes....I had a lot of them....In fact, maybe all the side effects. I had nausea. They gave me the anti nausea medication. I am not sure whether it really works or it was just me. Maybe it was psychological. Whenever I took it, I just kept worrying, thinking that I was going to feel like throwing up anyway and that I would not feel like eating. In fact if it were for me I would avoid the treatment because the only thing that rang on my mind was that treatment is going to make me feel worse than the cancer itself” (Participant B, 19 October 2006).

"I would throw up all the time. The situation would remain that way on Thursday and Friday, and on Saturday I would start lifting myself up but I would still be tired and could not even feel my joints. I would try and regain all my strength only to go back to the same thing the following month. This made me really scared whenever it was about time to go for chemotherapy sessions, In fact I would just freeze when thinking of what would come after that" (Participant C, 22 October 2006).

Another excerpt from participant C, 22 October 2006 is as follows:

"It was strange and difficult to shift from being healthy and all of a sudden being sick and not just sick but critically sick and wanting to believe that you will be fine but having no guarantees to that despite your hope and faith. And I was anxious about losing my hair. I read on the side effects and watched TV shows where they talked about cancer and how its treatment causes hair loss."

"The thought of chemotherapy just made me freeze before I began the treatment. Then came the thought of being unable to move after chemotherapy sessions, I knew that I just wasn't going to be able to do anything after chemo..... If I didn't have people monitoring and following up on my treatment, I would actually stay away by choice because the treatment was worse than the illness."
(Participant, E 10 December 2007).

- **Anxiety about exhaustion of financial resources**

Despite the majority of the interviewed participants having had access to medical aid funds as well as stable employment (except for one participant), anxiety over exhaustion of funds did surface in one participant. This participant worried that her medical aid funds would be exhausted, thus posing a threat to her treatment. What is important to note with this participant's case is that her cancer was diagnosed at a late stage hence she had to undergo a lot of tests aimed at tracking down any further spread of the cancer. Unlike the other participants, she also experienced the major side effect of a shortage in white blood cells which proved taxing on her medical cover. During the treatment process, Participant D, 27 October 2007 also lost her fiancé with whom she had been living and decided to relocate to another city following this loss. All this extremely exhausted her medical funds as well as her own monthly income, while she no longer was guaranteed of financial support as much as she would have been if her fiancé were still alive. This is how this participant articulated their anxieties over finances:

"Oh yes...I had a medical aid but at some point it got exhausted and I was practically financially drained out. I had already seen the exhaustion of funds coming because I underwent a lot of tests and I could not help but panic because I was already on treatment and the running out of funds could only mean that at some point I was going to have to stop treatment and perhaps opt for the public health system which is not so pleasant."(Participant D, 27 October 2006).

- **Anxiety over negative changes in relationships**

Four participants expressed anxieties about the possibility of relationships being impacted negatively by the diagnosis and treatment. Participants appeared to have experienced worry about the negative impact of their diagnosis on their intimate relationships. Participants B, C, D and E, reflect this well in the following excerpts:

Participant B, 19 October 2006 was already married with three children at the time of diagnosis. Her husband's not receiving the diagnosis very well and his obvious lack of communicative or expressive ability coupled with the couple's experience of negative side effects on their sexual relationship, made her anxious about whether her marriage would survive the cancer.

"The book did tell me about the side effects but hey.... sometimes you just promise yourself that you will be an exceptional case and not have all the side effects. My husband did not receive the diagnosis so well and this made me fear the worst for our relationship. Obviously he was taking strain and I started being preoccupied about him getting fed up and leaving me at the time when I needed him. That thought really scared me' (Participant B, 19 October, 2006).

The following participant's relationship was reported to have adjusted well to the diagnosis before the participant's fiancé passed on, however, the participants had both her breasts removed and had difficulty with side effects. This therefore contributed to her feelings of anxiety over negative changes in her relationship.

“But I must say that I feared that it was soon going to be all over but he was always there” (Participant D, October 27 2006).

Participant C, 22 October 2002 also became anxious over the possibility of treatment impacting negatively on her relationship. This was despite her marriage being well adjusted at this time. This is how she expressed her anxiety:

“Well, I have always been grateful that at least I had the opportunity to operate on it before it was too late.... So...before the actual operation I was very negative towards operating, but at the end of the day what was more important was my life and my husband assured me that whatever difference the operation would make, we would be able to pull through it. I mean, there is really not that much of a difference except that my one breast is smaller than the other” (Participant C, 22 October 2006).

It also came across that for a woman in a relationship that was already experiencing difficulty even prior to the breast cancer experience, anxiety about further disintegration in the intimate relationship existed as illustrated by a quote from Participant E, 10 December 2006.

“At the time when I was diagnosed, my relationship with my husband was already not going well and when I was diagnosed, I just could not stop worrying over how

things could get worse, especially when they told me I had to lose my whole breast. Apart from just worrying, the relationship really did get worse. My husband is just more distanced and does not ever openly talk about the experience and we just practically no longer have a sex life And things really did get worse.....” (Participant E, 10 December 2006).

(iii) Stress and coping

All the participants reported increased stress levels as a result of the practical impact of the treatment regimen on their lives. The illness demands at times proved to be beyond their available coping resources. The main areas in which increased stress levels manifested were, work, family as well as traveling arrangements.

Three of the participants reported having had to travel to Durban for radiotherapy sessions as these services were reported to not have been available in the Pietermaritzburg area. Of all the participants that travelled to Durban for radiotherapy, none had private transport that belonged to them. Two of these participants did however, manage to cope with the situation as they had individuals who had access to private transport and who availed themselves for assistance.

An example of such coping with practical illness demands as a result of the availability and utilisation of support in this regard, is clearly illustrated by the following quote from

an interview with Participant A, 02 October 2006. The quote also highlights on usefulness of support networks which will be looked at in a latter section.

“I had a friend who was very supportive and availed herself all the time. She offered to drive me around anytime so much that she even offered that if she was not available to drive, then I should get somebody to drive in her place. I took my treatment in two places. Chemotherapy was here in Pietermaritzburg at St. Anne’s and Radiotherapy in Durban” (Participant A, 02 October 2006).

For Participant C, October 22 2006 however, this was not the case as she had to travel to Durban five days a week for six weeks for her treatment sessions. Participant C was particularly stressed by this arrangement as she did could not be guaranteed access to private means of transportation. Meanwhile the immense side effects she experienced following each session worsened the stressful experience of having to travel for treatment. This is how she related her experience:

“Well.... I had just started working and was getting paid very little at the time and therefore I did not have a car. I took taxis everyday and sometimes my husband would fetch me at the taxi rank. I would get there to find him waiting for me. But he could not do this everyday because he had to work. So perhaps for 3-4 days in a week, I would have to catch a taxi. It was very frustrating ... (pause).....It was difficult at times when I finished the session and felt dizzy but still had to go and

catch a taxi. I would also have a running stomach at times” (Participant C, October 22 2006).

Issues related to careers also proved stressful for three of the participants in the current study. There were indications that it was either participants felt they had to honour their responsibility in their place of work or their employers could not take quite easily to their constant absence from work. Participants A, 02 October 2006 and Participant B, 19 October 2006 were such individuals who felt that they had to see to their responsibilities despite the illness demands being taxing on their physical ability and therefore their ability to cope at work.

The participant quoted below was the only breadwinner in her family and for her, bringing in an income served more than just her personal needs but those of her family too hence it was imperative that she continued working and this was much more so because she had recently started working.

“I used to force going to work and when I got there, I could not work at all. For example, when trying to write on the board, I would feel tremendous pain as I tried to lift my arms. I just couldn't. I was practically getting paid for nothing but kept insisting I was going to be okay with God on my side” (Participant A, 02 October 2006).

For Participant B, 19 October 2006, her source of stress was not significantly dependant on her having to generate an income, but it was related more to her sense of responsibility towards her work.

“My seniors were very understanding at work. I would sometimes force going to work because I felt bad since I teach a grade twelve class and its critical that I do my work and despite my colleagues always covering up for me, I still felt about not fulfilling my duties if I wasn't able to finish the day at work or could not go at all” (Participant, B, 19 October 2006).

It also emerged that not only did some of the participants feel compelled to present themselves for duty despite the circumstances, but one of them was in fact experiencing difficulty with her employers as well. This was the case for Participant C, 22 October 2006, as it was not only imperative that she continued working because she could have found it difficult to secure another source of income if she left or did not work often, but she also sensed tension in her workplace at those times when she could not carry out all her duties due to reasons of ill health.

“Well....I had a really bad job, working in a flower shop and it was a family business. In a way I was at their mercy. I guess they allowed me to go whenever I needed to but they were not really pleased with that and sometimes they would complain and at times I could just read between the lines. It was bad, especially when I had to go for radiotherapy treatment because it was either I could not go

work at all or I would have to leave early. I just figured I needed to come to work whenever I could because my chances of being fired seemed to increase each time I could not come. At the times when I was at work I had to be strong while in actual fact most of the time I was in pain and could not do my job as best as I used to”(Participant C, 22 October 2006).

Another factor that was reported to increase participants’ stress levels, particularly for those who were caregivers, was that of not being able to care adequately for their families. The time and energy involved in running a household and thus caring for families, demanded more than they could afford in-between their appointments and the pain. Even though being part of an intact family provided much needed support, participants felt that they were being a burden to others. This was the case with married participants and with the participant who was engaged to be married and shared a home with her partner. Below is an example of how one participant felt she was burdening the person who offered assistance.

“She did a great job with the children and I always felt so bad because at her age she was really meant to be resting peacefully not taking care of children. But she always assured me that she enjoyed the task” (Participant C, 22 October 2006).

(iv) Body Image Perceptions

With regards to participant’s body image perceptions, differing yet meaningful variation prevailed. First and foremost, amongst all participants, it surfaced that the operation on

the breast outweighed the possibility of death as a result of breast cancer. All the participants in the current study saw the disfigurement resulting from the breast operation as marking a second chance to life. Below is an example of how one of the participants regarded the disfigurement.

“So ...yes...at times I do feel sad and frightened by the whole change, but I am getting used to it now, especially since people cannot see the change, not unless they know. But overall, I feel lucky. It is much more better that I have an altered breast than being dead or having no breast at all” (Participant B, 19 October 2006)

It did, however, appear that despite the recognition that having one’s life was more important than the disfigurement, for participants whose one or two breasts had to be completely removed, while appreciation for having one’s life prevailed, this appreciation was accompanied by ongoing and immense difficulty adjusting to and living without their breasts. This difficulty emerged to have been more related to the breast being symbolic of the female identity and thus a perceived imperfection or incompleteness in the female identity as a result of the operation. The two excerpts below illustrate the difficulty these participants continue to experience.

Participant E 10 December 2006 was married and aged 31 at the time of interviewing. She had had one breast removed. Her relationship with her husband had already not been going well before diagnosis and she felt that it had in fact gotten worse. This participant

had originally had big breasts hence the difference between her two breast areas became distinctly visible when she had one breast removed. It seemed this participant's body image difficulty had been worsened by the difficulty that her relationship had taken as she felt that the change in her body image was not going to help her attempts at improving the state of her marriage.

"It is taking quite some time to get used to my body with the way it is now. The mirror is no longer a pleasant sight when I am getting dressed. And sometimes I wonder whether the operation is part of what is making our relationship worse. I mean....lately; we hardly make love let alone be naked in the light for a long time. There is also a huge difference in the size of my breasts as you can see(points to both breasts). I originally had big breasts and having the other breast area flat is really difficult for me, it just doesn't feel right as a woman and it is difficult getting used to it.....(cries)....but I'll be fine.....it is better than dying"
(Participant, E 10 December 2006).

In responding to question focused on body image perceptions, Participant A, 02 October, 2006 expressed her perception of her body image following the removal of her breast as follows:

“It hurt.... it felt bad, I do not want to lie. When I put a bra on for the first time after the operation, it really hit me....eehh....I kept asking myself what kind of woman had I become, a woman with no breast. (Participant A, 02 October 2006).

In responding to other questions, the same participant expressed what clearly revealed that her difficulty adjusting to the change in her body image had led to her perceiving herself as unattractive and undeserving of male attention. It is important to note that of all the participants, she was the youngest at the time of diagnosis and also went through a phase where she was single after the tragic loss of her partner, though married at the time of interviewing. Below is an extract highlighting the participant’s feelings and perceptions in this regard:

“But more than anything else, I found myself always thinking and being convinced that nobody will ever love me because of the scar and I am very sensitive in the area with the scar. You won’t believe that I still feel uncomfortable around him when I am naked (her husband). He also knows and leaves me alone most of the time when I am taking a bath or getting dressed”
“You know I believe I am a person with a very strong character but up to this day, whenever I am getting dressed, I still get disturbed because I cannot just wear anything. I cannot just reveal. Even when I am buying clothing, I can’t buy all the things that I like because my scar is very large and visible so I have to buy something that will be able to cover up”(Participant A, 02 October 2006).

The participant whose quote follows below was single at the time of interviewing after also having lost her partner during the treatment process. She was also the second youngest in the group of participants interviewed for the study. Choice of clothing as well as social activities proved challenging to this participant as she felt that these were central to her feeling acceptable as well as attractive as a woman. This participant's had had both her breasts removed.

“My sister likes clubbing and you know with clubs, there is a certain way of dressing and most of the time, tiny revealing clothing items are fashionable in clubs and parties. So when my sister proposes that we go out, I just think of my skewed chest area and end up deciding to stay in. It is really no longer the young and attractive type of body that one would want to show off at a party. This really isolates me sometimes. I worry when I think of the possibility of meeting a new guy as he might not understand nor find me attractive” (Participant D, 27 October 2006).

(v) **Appreciation of life/ View of life**

Overall, the breast cancer experience appeared to have increased all the participants' appreciation and view of their lives in general. It emerged in the interviews, that the breast cancer experience brought upon participants, a realisation that they need to make the most of their lives and appreciate their health and vitality. Participants reported having realised, after surviving breast cancer that there was more value to their lives than they had previously realised. Some of the participants also reported having started seeing

themselves as people who are destined to grow stronger in life, excelling in all they set out to achieve. They also defined themselves as lucky. Below are quotes of how participants felt that the breast cancer experience has impacted on how they see themselves:

“You know as a young woman, I think seeing yourself as an attractive person is very important and I think at this point I battle with seeing myself in that way because of the operation. But at the same time as a young woman who is part of a family and part of a society, I think it has given me a wake up call, to say that I just have to live my life to the fullest and make as much of a difference to my family and society as possible, in whatever way, because you only live once and I am lucky to have been given a second chance” (Participant D, 27 October 2006).

“And you know, more than anything else, I think the cancer came by to remind me that I am a beautiful, young and intelligent woman and I need to appreciate and use all of that. I just have not been doing much with my life, that is why I am saying the new me is about to be seen” (Participant B, 19 October 2006).

“ It has taught me to value each and every part of my body no matter how small because once you loose it, you miss it terribly” (Participant A, 02 October 2006).

4.2. SOCIAL IMPACT

(i) The Partner Relationship and Sexuality

For participants who shared a home with their partners, adjustment to activities within the home was reported, for instance, where the male partner had to take on more responsibility with the children. In this regard, partners were reported as supportive throughout. None of these participants' partners were said to have left or threatened to do so at any point. There were however, reports of a disruption in the sexual relationship. This disruption was said to have been due to factors such as pain, and complications brought about by treatment side effects such as loss of libido.

Participant A, 02 October 2006 lost her partner during the treatment process. Later in her life she met someone else and has gotten married. She reported having experienced difficulty in her sexual relations as a result of the long-term effects of the removal of her two breasts. She still feels pain in her chest area as a result of the operation.

“It is bad...you need somebody who will understand you and really love you. There are serious complications sexually..... When I have sex with my husband, he has to avoid leaning on me and constantly keep in mind that he might hurt me”
(Participant A, 02 October 2006).

“After finding out that I had cancer, we weren't really engaged in any sexual relations. Mainly because we were both shocked and were taking the time to process this. And also, everything happened so fast, I did not have time for sex

really. I was diagnosed and was meant to go for an operation the following week...that was before the operation and after the operation I had to take care because the breast area was still very sore.... The chemotherapy made it worse. Well at the beginning I was okay, despite the side effects we did have a sexual life. But towards the last chemotherapy, I just lost my libido....I was just more like a stone....My husband did not take this so well. Obviously he was taking strain.... Thanks to a friend of his who is a pastor, to whom he confided about our problem” (Participant B, 19 October 2006).

“Well, it became complicated sisi. I felt pains in my body for most of the time, then obviously we had to abstain but he understood and never forced anything. But I must say that I feared that it was soon going to be all over but he was always there” (Participant D, 27 October 2006).

For these three participants therefore, the effects that the breast cancer experience impacted on the sexual relationship were not at any point said to have yielded any disintegration in participants' relationships with their partners nor were the partners reported to have engaged in extramarital affairs for married participants. However, this sexual impact yielded a link between sexual difficulties and participants' anxiety as the majority of them became anxious over the possibility of partners finding them unattractive and leaving because of the lack of sexual activity and this was despite the absence of an indication of such a possibility. The excerpt below is an example of such anxiety:

“... And this made me fear the worst for our relationship. Obviously he was taking strain and I started being preoccupied about him getting fed up and leaving me at the time when I needed him... So in other words we are having difficulty with our sexual life but it hasn't really reached a stage where things are complicated because we have an understanding and I am hoping that things improve because we are still too young to have a problematic sexual life and have our future to look forward to” (Participant B, 19 October 2006).

For Participant E, 10 December 2006 however, it seemed that her relationship did indeed fail to handle the strain. What is critical in noting this participant's experience is that her marriage had already been experiencing difficulty even before diagnosis. Below follows an excerpt capturing the participant's experience of her marriage and intimate relationship during the breast cancer experience.

“Apart from just worrying, the relationship really did get worse. My husband is just more distanced and does not ever openly talk about the experience and we just practically no longer have a sex life” (Participant, E 10 December 2006).

In addition to challenges faced by intimate relationships in adjusting to the diagnosis, two of the current study's participants experienced even more difficulty, as they found themselves without partners as a result of their partners tragically passing away during the process. These participants reported that following their partners' deaths, they

experienced a new set of anxieties. These anxieties were around meeting new partners with regards to how these new partners might react after hearing about the diagnosis as well as their reactions to the two participants' only having one or no breast. These participants were Participant A, 02 October 2006 and Participant D, 27 October 2006 who also were also experiencing greater adjustment difficulty as they were the youngest at diagnosis compared to the whole group and had had one and both breasts removed respectively.

"I wrote off the idea of marriage because, I have a permanent and frightening scar and secondly, I am very sensitive in the area with the scar. I thought if I were to have sexual intercourse, than the partner would hurt me physically"
(Participant A, 02 October 2006).

"I worry when I think of the possibility of meeting a new guy. He might not understand nor find me attractive" (Participant D, 27 October 2006)

It became difficult to establish any other effects on the partner relationship as participants generally described their partners as having been affected by the diagnosis but also not being that open and expressive about their emotions.

(ii) Social Networks: Friendships and Extended families

While immediate and extended families were reported to provide practical and emotional support, the participants also reported feeling that their illness was a burden to their families. Each respondent reported that their family's spontaneous reaction was that of shock and worry about death. In addition to this however, depression set in some of the families as they were confronted with the patient's illness and had started anticipating death. Most of the families had been through some stressor, especially related to loss and the diagnosis of breast cancer evoked memories and put strain on the family's coping. This suggests that the illness was an additional source of stress for the family. The following quotes aim to capture family's experiences of the breast cancer experience.

Participant A, 02 October 2006 was the sole source of income in her household, providing for both her siblings as well as her elderly parents. Her illness thus proved threatening to the family's survival as should she have passed away, the family would have had to go back to live a life of poverty.

“Oh at home, it was difficult because I am the first born and the bread winner so they felt bad that I could no longer work and who was now going to buy groceries.” (Participant A, 02 October 2006).

The family of Participant B, 19 October 2006 on the other hand had been through a series of losses following illness. Being the participants' siblings, individuals who had passed away had left children of young ages who needed looking after. The possibility of her

dying, though not explicitly expressed, seemed to pose the threat of this already existing burden.

“All in all I would say that my family did not receive it very well, they became very worried, especially my mother as she felt she knew what the diagnosis meant. To her, it meant that I was going to die just like her mother. And she started recollecting, recalling that my other sister and brother had died and left their very young kids and this meant I was also going to die and leave my kids at such a tender age. She just saw the cancer as coming to sustain the pattern” (Participant B, 19 October 2006).

Relationships with friends and colleagues at this time appeared to have been confused, strained and tested. Firstly, despite friends and or colleagues having surfaced as sources of support for all participants, it did however, appear that participants did not rely heavily on such individuals as some did not understand the illness or were angry about participants having to increasingly take time off work. At times it was also expressed that what contaminated participant’s relationships with their friends and colleagues was assumptions from such individuals that participants were HIV positive but thus will be referred to in detail in the sub-theme “HIV/ AIDS”.

“Well...the people I confided in are mostly my colleagues and the people I go to church with. The people from church were there for me. Well.....with my colleagues..... you know.....there is always work politics so they were kind of

divided. Some were genuinely supportive, some were indifferent while some were saying all kinds of things when I had to take time off work, they were never happy about that at all.” (Participant E, 10 December 2006).

An aspect of note is that due to all participants’ strong religious backgrounds, people from their churches formed much of their social network and served as sources of support apart from friends and colleagues.

(iii) The mother-child relationship

Of the participants who had children at diagnosis, actively taking care of their children was at times impossible as they were physically unable to fulfil their motherly duties. Tasks relating to childcare and rearing therefore had to be delegated to partners and family members who availed themselves. Their children were reported to have been saddened by the diagnosis and there were also reports of participant’s children being anxious with regards to the course of the illness.

“I mean, he is a boy so he did not really express how he felt that often but it still came across quite clearly that he was saddened by this and did at times ask what would happen if it got worse and what would him and his father do without me” (Participant C, 22 October 2006).

“They asked how long I was going to be in hospital and I told them it was going to be for six days” (Participant B, 19 October 2006).

Seemingly therefore, there were times at which mothers could not be there to take care of their children thus temporarily distancing the mother-child relationship. What was striking with one participant was how she utilised the smallest chance she got to actually explain to her children, what was going on, what they should expect and how she felt. As a result of their mother opening up, these children also opened up and adjusted well to their mother's situation as quoted below.

“ Oh yes....I did. In fact, I had to because I had to go to their schools as well to tell their teachers because their schools always advise us that if there is something wrong at home, no matter how minor, we have to inform them. So I decided to tell them first so that when their teachers ask how mommy is, then they would know what the teachers were talking about and also just for me to give them information on what cancer is”I allowed them to touch the lump. I told them that mummy is going to hospital and is going to have the lump removed through operation. I also told them that when I wake up from the operation, I would have a scar because of the operation” (Participant, B 19 October 2006).

The excerpt below illustrates the positive impact that this participants' openness had on her children's anxiety and their coping with the anxiety therefore:

“I also believe that the main helpful thing was the fact that they were aware of what was going on, every step of the way. You knowthe one Sunday we were

coming from church and I asked them what they had done in their Sunday school class and they said that their teacher had asked whether any of the kids needed a prayer and they said that they needed a prayer because their mother had cancer and everybody prayed. I was happy they could talk about it because it showed that they were not bottled up about it and could easily talk about it. And it also showed me that they believed I could get better and wasn't going to die".
(Participant B, 19 October 2006).

4.3. OTHER EMERGING THEMES

(i) HIV/AIDS

There appeared to have been a confusion and disbelief, with regards to the nature of the illness amongst individuals in participants' social networks (these individuals included mainly colleagues and neighbours). Three participants in the study articulated that friends and colleagues assumed that the participants were not being honest about the real diagnosis and are using breast cancer to hide their HIV positive status. This proved hurtful as well as unsupportive to participants.

".... Others started gossiping which showed that they did not believe that I was not HIV positive. To this day some people still ask me what treatment I took because I had AIDS" (Participant A, 02 October 2006)

“But you know, the most difficult time was when they kept telling me that my fiancé would leave because I had only one breast. That just made me not trust the intentions behind all their support. Some of them thought I was actually HIV positive” (Participant D, 27 October 2006).

“I think one of the things that irritated me most with my colleagues was that some of them were claiming to be supportive while they were convinced that I was HIV positive but they just did not admit it to me, they would talk about it behind my back.” (Participant E, 10 December 2006).

(ii) Religion as a coping mechanism.

A pattern of the use of religion as a coping mechanism in the face of illness came across quite often during the interviews. Participants articulated having utilised religion as an explanatory model, seeking answers, strength and comfort from their religious affiliation. Members of the church were also reported by participants to have afforded participants great support. The excerpts below illustrate how participants drew support from their religion as well as from fellow church members.

“.....And my church was also very supportive; they came and prayed for me. That gave me the strength to go on” (Participant C, 22 October 2006).

“After my diagnosis I gave myself a closer relationship with God and that has always helped. The atmosphere in church has lifted my spirit throughout”
(Participant D, 27 October 2006).

“.....But the support from my church was massive and it helped in phasing out these why questions. When I woke up in hospital they were there, before my husband could even come” (Participant B, 19 October 2006).

“I was born again and kept telling myself that God cannot give me minor ailments that I could survive before being born again only to allow me to fall sick and die soon after being born again. I kept saying “God you said we should pray”
(Participant A, 02 October 2006).

(iii) Physical health Outcomes

It emerged from interviews with some of the participants that the experiencing of intense psychosocial difficulty, was highly likely to have contributed to poor physical health outcomes amongst participants going through heightened difficulty. This was particularly the case for two participants (Participant A, 02 October 2006 and Participant D, 27 October 2006) in the current study who both experienced two recurrences. The excerpts and background information below aim to capture these participants’ psychosocial experiences as well the participants’ difficulties in relation to physical health.

Participant A, 02 October 2006 had recently started working when she was diagnosed. She reported having experienced intense depressed mood in relation to being the breadwinner in her family and being faced with the threat of dying as a result of the cancer, leaving her family in poverty. While still faced with such difficulty, this participant also tragically lost her long distance and long term partner while she was still undergoing treatment and shortly after being discharged from hospital. This participant reported having later experienced recurrent cancer. This is how she related her experience:

“The second time around though, I was very sick. I went to the doctor and he told me that the cancer had come back and that the best thing to do at that time would be to remove the entire breast.....Then they removed it and that was 1996.....And after a year, that was 1997, I felt pains, the cancer had come back.....(Participant A, 02 October 2006).

Participant D, 27 October 2006 also reported adverse psychosocial experiences shortly before diagnosis as well as during treatment. The participant reported having lost her mother and sister shortly before diagnosis. While undergoing treatment, she also had her fiancé passing away. It was around the time of losing her partner that she reported having started experiencing immense side effects after treatment sessions for the first time. In the participant’s words, these side effects were highly likely to have been stress related than treatment related. **Participant D, 27 October 2006** also experienced two recurrences in

the same year that she had started treatment and had lost her fiancé. This participant's experience was captured in the following words"

"I then experienced back pains and had to be taken back to the doctor who had done the tests in the first place and there it was detected through MRI that the cancer had spread to my spine and they proposed an operation of the spine or radiation.....So in between the chemo sessions, I would go for radiotherapy sessions. After a while I was okay but after April I started experiencing terrible side effects. My white blood cells dropped massively. I also experienced other side effects that I had not experienced before but I think that was also linked to my fiancé's passing away because he passed away in April. I then moved to Johannesburg in May and started working with another oncologist. I was okay for a while but later on, I started feeling terrible pains along the ribs. The doctor found some dots and concluded cancer again and opted for radiation, which I have just finished today.I decided to go on leave after my fiancé's death because I think the side effects were also a result of the stress that the incidence brought" (Participant D, 27 October 2006)

CHAPTER 5

DISCUSSION OF RESULTS

5.1. Introduction

Research has increasingly shed light on the increased risk for psychosocial morbidity in younger women following a breast cancer diagnosis when compared to older women (Avis, Crawford & Manuel, 2005; Canadian Breast Cancer Network, 2002; CANSA, 2005). Indeed this comes as no surprise as breast cancer challenges well-being and threatens life and plans for life thereof. Young adulthood is a critical stage in the human development cycle, where independence, long term plans, dreams and hard work for some, are all expected to pay off and fall into place. In line with these expectations, young adulthood thus becomes a time where securing employment, achieving and advancing in the workplace, starting a family, seeing children off to school and being at the prime of one's life are all the more important tasks (Avis, Crawford & Manuel, 2005; Van Niekerk & Prins, 2001). Evidently therefore, for women of younger age, these activities are more than highly likely to be affected to a greater extent by the breast cancer experience as demonstrated by the results of the current as well as other studies (Sammarco, 2001; Turner, Wooding & Neil, 1998).

With the increase in breast cancer incidence rates in younger women, there exists a need to understand challenges unique to this group of women if health care workers at different levels are to intervene in relevant and thus efficient ways. To reiterate the aim of this study was that of gaining insight into how younger women's psychosocial worlds

may have been impacted upon by the diagnosis and treatment processes associated with breast cancer. This chapter thus focuses on imparting the knowledge learned from the women who devoted their time enlightening the researcher on their experiences in this regard; in an attempt to enhance various readers' understanding of the challenges encountered.

5.2. PSYCHOLOGICAL SEQUELAE OF BREAST CANCER

(i) Depressed Mood

Results from the current study revealed that participants experienced depressed mood in relation to the breast cancer experience and its demands. Findings highlighting the presence of depressed mood in participants were consistent with an observation made by Bennett, Goldstein, Llyod, Davenport and Hickie (2004), that women diagnosed and treated for breast cancer commonly report depression in relation to and as part of the challenges that accompanies the breast cancer experience in relation to their ability to function biologically, psychologically and socially. Though this finding was common across participants' stories, factors influencing the depressed mood did however vary depending on life histories and circumstances.

In the current study, participants' depressed mood was expressed through the use of phrases such as sad, teary and feeling like they had lost control over the situation. When one looks at the Diagnostic and Statistical Manual of Mental Disorders, the above-mentioned features, form part of the signs and symptoms of depressed mood (APA, 2000). According to Rosch (1984) the world of an acutely ill patient is not only

composed of physical pain but of psychological, spiritual, financial and social pain too; thus feelings of a loss of hope and of helplessness are characteristic of the world in which such patients live. These difficulties can be characteristic of any patients' world but there are unique features of a younger woman's experience of breast cancer as a result of their developmental stage and the activities relevant to this stage.

Consistent with the current study's findings, Avis, Crawford and Manuel (2005) indicate that factors likely to provoke psychological distress, including depressed mood, among younger women are often a result of concerns over issues such as fertility, ovarian decline, sexuality, body image, careers and having young children, all of which are developmentally significant concerns.

In line with these developmentally significant concerns therefore, thoughts around death were uppermost in the list of factors that provoked depressed mood in some of the participants and those close to them in the current study.

In essence, death constitutes the concept of loss, be it the loss of a loved one or the loss of one's life. Bohnet (1986) sees loss as an experience of deprivation from something precious and highly valued. Life is precious and valued, hence anticipation of a possible loss of life, whether by patients or their loved ones, has been found to often trigger depressed mood (Monesa, 2003). According to Horowitz (1979), the more that individuals anticipate their cessation from existence, the more they become aware of their

vulnerability and this awareness results in a shift to a weaker self image, one characterised by weakness, abandonment, hopelessness and helplessness, some of the features of depressed mood. Further, with the sometimes drastic nature of the physical impact of breast cancer, individual's vulnerability may not only be due to perceptions of vulnerability but also to the actual vulnerability posed by the illness' impact on physical strength.

It is important to note that the depressed mood arising as a result of thoughts around the participant's possible death and the implications thereof was reported to not only have been experienced by participants, but by those close to them as well. Those close to them in this instance included their children, their husbands or partners and family members such as mothers and siblings. With regard to participants families' experience of depressed mood, the results of the current study were consistent with the findings of a number of studies (Lovejoy, 1986; Maguire, 1981; Wellisch, Jamison & Pasnau, 1978), which report husbands and other family members as having significant psychological distress following a cancer diagnosis in a mother, wife or a daughter, mainly as a result of anticipated loss of their loved one to the illness.

A point of note at this point is how these thoughts appear to have been motivated by previous experiences of loss. Four of the participants' families had lost loved ones following illness. Of these four, two participants had also tragically lost partners during the treatment process. Accounts capturing depressive thoughts around death, clearly illustrated continuous association of current illness to prior loss, linking how breast

cancer diagnosis would eventually lead to yet another loss. Despite the paucity of literature supporting this finding, it did however, become evident that prior loss had a major role to play in influencing these thoughts around death as well as the resulting depressed mood in participants' families.

One participant's depressed mood was related to concerns about the economic well-being of her family if she should die given that she was the breadwinner in her family. This participant expressed a sense of an impending failure to fulfil her responsibility towards her family, thus threatening her family's economic wellbeing and survival.

For this participant, it emerged that having just started out in her career aggravated her depressed mood as she imagined how dying would prevent her from taking care of her family just when they had started enjoying the fruits of her work. In her view her family had done all they could to ensure that she could better herself and as a result, she had high hopes and dreams for herself and her family. According to Breast Cancer Care (2004), women diagnosed at a younger age with breast cancer are likely to experience and perceive themselves as being at a financial risk during this time compared to older women. This is purported to be due to younger women having had less time to work towards financial security. Further, they may be single and their income may be highly crucial to their household financial stability (Breast Cancer Care, 2004).

Though not explicitly expressed and thus not particularly a significant concern in the current study Soothill, Morris, Harman, Francis, Thomas and McIlmurray (2001), noted

an interesting dynamic that might also contribute to the onset of depressed mood in patient's loved ones during this trying time. These authors reported that often individuals close to cancer sufferers end up being their informal carers thus finding themselves sharing a lot in the illness experience. According to Soothill, et al. (2001), this makes it more than vital to constantly take note that these informal carers are not only important as support systems for cancer patients but also as people with psychosocial needs and even problems of their own at times, that might take a back seat during a loved one's breast cancer experience thus adding to already existing distress. This altruistic and moralistic explanation of carers' act of putting patient's needs above their own coupled with the exhausting difficulty of witnessing a loved one go through pain as well as anticipating the possibility of losing them provides some explanation for understanding loved ones' depressed mood at this time.

In addition to the possibility of an impending death as a result of the breast cancer, not being able to fulfil their role of being a mother and wife as a result of the illness served to exacerbate feelings of guilt, hopelessness and helplessness in some of the participants when faced with the reality that they could not be as strong as they would love to and as everybody would love them to be. Three of the interviewed participants were married, one lived with her fiancé and four of them had young children under their care while only one of the participants had no child under her care. The participants who had children in their care and lived with partners, came across as having ran their households in the traditional way, where as females they were responsible for household chores with the intention of ensuring that their children and spouses were well taken care of. This

traditional manner of doing things was obviously disrupted by the woman's ill health as at times participants would be feeling physically weak and thus unable to perform household duties such as cooking, washing, cleaning and bathing children.

The results of a study by Curt, Breitbart, Cella, Groopman, Horning, Itri, Johnson, Miaskowski, Scherr, Portney and Volgelzang (2004), revealed findings that are in line with the current study's findings when it comes to physical difficulty and issues around fatigue in cancer patients. These authors found that greater numbers of cancer patients experienced adverse physical symptoms in relation to the diagnostic and treatment process and that these symptoms had the potential to disrupt normal life, daily routine, social activities and at times cognitive tasks. In the current study, the symptoms included nausea, vomiting, acute and chronic pain and fatigue.

Silver (2004), reported that during this time, circumstance often forces families to adjust and often the male partner is required to take more responsibility for the household than previously. Indeed the interviewed participants did report this adjustment as well as support in this regard, particularly from their partners and various other individuals such as family members and neighbours. There were however, reports of sadness due to the fact that other people had to step in and take care of household duties that participants used to easily and willingly perform. Issues of guilt and questioning of how good they were as a mother or wife contributed to their depressed mood. Feelings provoked by their physical difficulties and inability to sustain families included feelings of worthlessness and guilt over their inability to actively take responsibility for pre-diagnostically routine

activities. These have been reported as commonly emerging feelings during times of physically taxing illness (Day, 1999; Monesa, 2003). These illness and treatment-related physical symptoms thus had a significant impact on the participants' quality of life during the breast cancer experience.

In addition to their compromised care-giving roles contributing to their depressed mood, their care-giving roles may have also threatened the support that was meant to be directed to them given their families expectations of them. A crucial finding from this study was participants' need to contain the feelings of depressed mood of their loved ones, through reassuring them that they were going to be okay. Mothers felt they had to be strong for their children and husbands, continuously assuring them of their love and support. The same was also evident in the two participants who had partners but were not married. Their partners also came across as having taken strain during this time. As Casileth (1985) and Noyes, Debelius-Enemark, Williams, Mutgi, Sueelzer and Glamon (1990) note, there exists a highly influential relationship between the psychological well-being of key relatives playing the informal carer role and the psychological outcomes for patients. There is thus a need for support and containment of informal carers, so as to enable them to cope with their own emotions and more effectively care for the psychological needs of the patient.

In addition to depressed mood arising due to thoughts around death and not being able to fulfil their care-giving, depressed states also arose as a result of an anticipated possibility of not being able to bear children. Medical research has long established that cancer

treatments, including that of breast cancer, pose a threat to fertility post treatment (Bennett, Goldstein, Llyod, Davenport & Hickie, 2004; Schover, 1997). As was the case for participants in the current study, irrespective of whether they had children or not, activities such as child bearing and rearing are developmentally appropriate for women of younger age.

Women who participated in the current study either had no children and were still hoping to have children or had very young children (infant to pre-adolescent) at the time of diagnosis but still hoped to have more children. These women were also well aware and saddened by the threat that the treatment process had imposed on their ability to conceive in future. Breast Cancer Care (2004) supports that indeed issues around fertility and reproduction are often of heightened concern to pre-menopausal younger women around the time of diagnosis, treatment as well as post-treatment as there comes a realisation of the threat that the illness and its treatment imposes on chances for reproduction. Developmentally, tasks such as starting a family and child bearing and rearing are appropriate to young adulthood (Kaplan & Saddock, 2003; Papalia & Olds, 1992; Van Niekerk & Prins, 2001). Hence participants' experiences of depressed mood in relation to their anticipated inability to reproduce as a result of the negative impact of treatment on their fertility makes perfect sense in light of their developmental stage and tasks relevant to their developmental stage.

The sadness evoked by thoughts of not being able to bear children in the future was heightened for two participants in particular, both of whom had lost partners during the

breast cancer experience, with one of them still not being in an intimate relationship during the time of interviewing. These participants highlighted their anticipation of the possible lack of understanding from new partners as well as the delay that meeting someone new and getting to know them may be effected by their compromised fertility.

When some of the participants related their experience of depressed mood, the researcher noted the presence of fatigue. There were instances of extreme tiredness and feeling dizzy. Despite the lack of adequate measures to differentiate between depression and fatigue in the current study, it is worth noting that the symptoms of depression and fatigue (due to pain and treatment) tend to overlap, where symptoms of fatigue may be mistaken for psychological symptoms and vice versa (Bernett, Goldstein, Llyod, Davenport & Hickie, 2004). This then clearly highlights the need for careful screening for both the psychological and medical explanation of many symptoms.

Whether evident in participants or those close to them, depressed mood surfaced at varying points during the breast cancer experience and for varying reasons as well. This then clearly demonstrated therefore, that each phase, be it diagnosis or treatment, brings its own relative challenges as authors such as Burgees, Cornelius, Love, Graham, Richards and Ramirez (2005) suggest.

(ii) Anxiety

According to Barlow & Durand (1999) anxiety is a mood state that is future-oriented in nature. Characteristics of anxiety include negative affect, the physiological symptom of heightened arousal and tension as well as apprehension about the future, perceptions of lacking control (APA, 2000). Linde, (2000) and Schlebusch and Van Oers (1999) assert that anxiety states are appropriate and typical reactions to the diagnosis and treatment experience of cancer.

Similar to signs of depressed mood, results of the current study suggest that the participants experienced signs of anxiety and fear which occurred across different phases of the cancer experience. Contrary to Lyons' (2004) presentation though, that pre-diagnostic anxiety is of clinical concern as individuals start anticipating a positive result upon and after undergoing testing procedures and while awaiting results, participants in the current study did not report any feelings of anxiety prior to, during or immediately after screening for breast cancer. This might have probably been due to the fact that none of the participants actually took the lumps or the pain seriously to the extent of anticipating a diagnosis of breast cancer. There were however, reported states of intense anxiety upon receiving the diagnosis as individuals and those close to them feared the worst in relation to the likely course of the illness. Monesa (2003) supports that in experiences of illnesses deemed life threatening such as cancer, indeed there does arise anxiety over what might happen next.

Anxiety in relation to the treatment process also surfaced in the results of the current study and this anxiety was specific to the side effects of treatment. Cancer treatment and breast cancer treatment in particular, is generally infamous for its unsettling side effects such as hair loss and nausea. Participants reported being informed by their medical practitioners or having found out through reading and through friends about the potential side effects of the treatment processes. This information was said to have served to heighten their anxiety over the treatment process. Two of the participants ascertained that to them the effects of the chemotherapy session became worse than the cancer itself as they could not move let alone bathe themselves after a chemotherapy session. These participants thus found that the thought of even skipping or avoiding treatment, so to speak, crossed their minds a number of times, with one particular participant indicating that she became 'numb' at the thought of a chemotherapy session.

A study by Atkins and Fallowfield (not dated) revealed that patients undergoing breast cancer treatment tend to avoid their treatment through subconscious forgetfulness or as a simple intentional choice not to adhere to the treatment. The findings of these researchers' study clearly demonstrated that younger women tended to not adhere to their treatment more when compared to their older counterparts as they often disliked the extremely unpleasant aspects related to the side effects of their medication. Atkins and Fallowfield (not dated.) further state that such patients who deliberately missed their medication were likely to have viewed themselves as having reduced control over their health.

Participants in the current study did not, however, report anything more than mere thoughts of skipping their treatment in anticipation of its dreadful effects. In essence such behaviour is a strong indication of anticipatory anxiety, where patients' thoughts become occupied with imaginations or recollections of unpleasant side effects. Findings of the current study are thus consistent with the findings of a study conducted by Jacobsen, Bovbjerg and Redd (1993), which revealed that indeed younger women do tend to experience greater anticipatory anxiety in relation to treatment sessions, particularly those for chemotherapy, as this group of women often anticipate and experience greater physically disruptive effects of treatment which in turn impact on significant areas of life, such as careers and family. The most crucial factor with this finding is that this anticipatory anxiety is likely to result in patients attempting to avoid the treatment process and that this anticipatory anxiety is linked to trait anxiety (Fredrikson, Furst, Lekander, Rotstein & Blomgren, 1993; Jacobsen, Bovbjerg & Redd, 1993). Trait anxiety is concerned with individual's prior anxious tendencies. This therefore calls for careful monitoring of the treatment process as well as careful consideration of prior psychological functioning.

Despite the majority of participants being on medical cover, anxiety over the exhaustion of funds was however, of concern. An exhaustion of funds would have had negative implications for the treatment process where participants would have been at risk of having their treatment process halted. This for participants would have proved life threatening as most of them had just recently started with formal employment and could therefore not afford financing their medical care any other way and some also had young children that needed catering for financially. The Canadian Breast Cancer Network

(2002) and Lyons (2005) do indeed support that financial concerns become one of the most significant areas in younger women's lives due to their developmental stage and the limited resources they might have been able to acquire at this stage.

As mentioned previously, breast cancer treatment can have unpleasant side effects. Apart from just the side effects and depending on the type of surgery, concerned women can be left without a breast or with a huge scar that provokes emotional and social scars too. These effects may often interact with and impact negatively on their intimate relationships. At this point in the discussion, the focus is not on body image perceptions as such, but is concerned with participants' perceptions and anxieties over their relationships as a result of the impact of the cancer and its treatment. Participants in the current study reported being anxious over the possibility of relationship disintegration due to diagnosis and treatment procedures. Four participants in the current study reported having experienced worry over the possibility of the treatment impacting negatively on their intimate partner relationships, despite the lack of any indication of such an impact. Only one participant in the current study had anxieties motivated by her intimate relationship's dysfunctional state prior to the diagnosis.

It is important to distinguish that for four of the study's participants, the anxiety over a change in relationships was evoked by participants' anticipation of their partners' reaction and not necessarily the actual reaction from their partners. Thus by the time the intimate relationship experienced difficulty (for those whose relationships did), the female partner had long been caught up in imagining what their partner's reaction to certain things would be.

Participants' anxieties centred on the following issues:

1. Partners' leaving them as they were posing an emotional, physical and financial burden.
2. Partners finding them unattractive either because of a reduction in breast size or because of the complete removal of the breast.
3. Partners failing to withstand the impact imposed by treatment on sexual activity, for example, vaginal dryness and the loss of libido.

Two participants in the current study had anxieties that were in fact linked to the state of their intimate partner relationships. One of the participants had been in a relationship that was well adjusted prior to diagnosis but took strain during the breast cancer experience. The second participant's relationship on the other hand had already been experiencing difficulties long before diagnosis. In the case of these participants however, it appeared that the difficulties experienced were not necessarily directly linked to breast cancer diagnosis and treatment but rather to personal characteristics as well as characteristics of their relationships prior to the diagnosis. Such characteristics included a lack of expressive or communicative ability from the male partner as well as being in a long distance relationship, which had not been going well long before the breast cancer diagnosis.

Looking at the other couple's experience of a lack of communicative ability regarding the cancer, Baider, Andritsch, Goldzweig, Uziely, Ever-Hadani, Hofman, Krenn and Samonigg (2004) support this finding through their assertion that when male partners avoid or fail to openly talk about the cancer experience, distress is highly likely to increase in patients. Male partners' failure to openly communicate about the illness may be due to a longstanding lack of communicative ability but it may also be linked to their attempt at hiding their feelings under the perception that they are being protective towards the ill partner's feelings while the female partner may interpret this as insensitive and as marking a threat to the solidarity of her relationship (Baider, et. al., 2004).

On the other hand, Taylor-Brown, Kilpatrick, Maunsell and Dorval (2000) assert that in intimate partner relationships that already have existing difficulties, indeed it is likely that breast cancer patients at this point grow anxious because there is increased chances that such couples may not have the coping mechanisms and solidarity needed for them to cope with and survive this challenging process.

For the rest of the participants, anxieties were there on participants' side but no negative impact on relationships was reported. According to Taylor-Brown et al. (2000) there does exist a frequent belief among women with breast cancer that they are bound to be abandoned by their partners as a result of breast cancer, particularly in younger women, for amongst this group, perceptions of attractiveness are still very crucial. These authors further maintain that this does not only affect diagnosed women but women in the general population too as they may put off screening and treatment for a suspicious lump seeing that a threat to the breast which may also mark a threat to their intimate relationships.

It does also appear that the media has had a large role to play in this misconception through its portrayal of the breast as having an inherent ability to attract a mate and as being the main seat for sensual and feminine attributes (Jade 1999; Taylor-Brown et al. 2000; Thorne & Murray, 2000).

(iii) Stress and Coping

Greenberg (2002) defines stress as an experience whereby individuals feel that current demands are beyond their coping resources. Factors that the aforementioned author identified as being the common sources of stress include a threat to health and survival, a preoccupation with situations that are deemed out of one's control as well as working or living under harsh conditions. A diagnosis of breast cancer therefore has the potential of marking a stressful period in the lives of those concerned as a number of adjustments have to be made in order to meet the various challenges brought about by the experience while individuals' health and lives are simultaneously facing threat (Spiegel, 1997).

Accounts of increased stress levels amongst participants in the current study centred mainly on the practical impact of the treatment regimen on their lives as practical demands proved beyond their available coping resources at times. The areas in which increased stress levels were reported were travelling arrangements, family and work. For instance, for three participants who had to travel to a different city for chemotherapy sessions, such travel arrangements in the midst of an absence of access to private transport and without the energy to drive even when private vehicles were available marked a significant challenge.

The stress experienced by participants in relation to their work clearly demonstrated that even though the advancement in breast cancer treatment contributed largely to surviving the illness, the treatment process was, however still regarded as being fraught with challenges that extended to the workplace for those who were employed at the time of diagnosis. Participants reported being faced with a double burden where they felt they had a responsibility to consistently carry out their duties during this trying time while at the same time employers were not tolerant enough of their constant absences from work. A study by Pryce, Munir and Haslam (not dated.), revealed that the symptoms of fatigue and stress were emphasized in cancer participants who continued working during treatment as well as those that had gone back to work immediately after the treatment process. This had implications for both employees' productivity at work and most importantly for their physical and psychological health outcomes. For women of younger age, this presents a greater challenge as employment may be highly crucial to their survival compared to older patients. Baanders, Andries, Rijken and Dekker (2001) suggest that work adjustments (such as physical environment adjustment and flexible work arrangements) that consider patient's limitations can play a major role in helping employees manage as well as keep their employment while not jeopardising the treatment process in any way either.

Research has revealed that there appears to be a lack of advice and guidance from health care practitioners for employers and the workplace that could be helpful for patients (Main, Nowels, Cavender, Etschmaier & Steiner, 2005; Maunsell, Brisson, Dubois, Lauzier & Franser, 1999). There is thus a need for a more integrated approach to support

extending beyond just the physician to include inclusive support from health care workers as well as workplace management.

It also emerged that for a participant who was the sole breadwinner in her family; feelings of financial responsibility worsened her experience of work related stress. Further, the form of employment also appears to impact differentially on stress levels. It seemed that working in a non-professional, wage-based environment aggravated the stressful experience of one participant's work. For this participant in particular, over and above her sense of responsibility towards her duties and her employer's reported lack of understanding was the challenge of not generating enough income following the times when she had to miss work. According to Avis, Crawford and Manuel (2005) career and finance related challenges are indeed often a frustrating issue for women of younger age as they may have just started with work at the time of diagnosis and probably have younger children and other related costs.

Another factor contributing to participants' stress levels was the challenge of caring for their families while ill, particularly for those who were caregivers. In the face of a life threatening illness, doctor's appointments and pain, such a challenge proved to be very stressful. Such stress can be said to have had influence on depressed mood as participants started feeling as though they were incapable, a burden to their families as well as feeling guilty and sad at not being able to meet these demands. Day (1999) and Monesa, (2003) support that indeed such feelings are common and appropriate to women going through the cancer experience, especially if they are family orientated and upon finding themselves unable to maintain the routine activities of their household.

Despite participant's reports of rather stressful experiences in relation to practical issues relating to the breast cancer experience, this experienced was reported to be alleviated by support provided by family members and friends who pledged and provided various forms of support to participants whenever necessary and possible. This finding clearly illustrates and supports the findings of Pistrang and Barker (1995) who found that positive and nurturing close relationships contribute significantly to alleviating the stress brought about by the breast cancer experience thus enabling patients to better cope with the illness.

Given that the majority of individuals in the current study were from relatively affluent backgrounds, these individuals and their families had better chances of affording the majority of the things they needed at this time. For instance, despite not having their own vehicles, the participants either had partners or friends who could provide transportation and in cases where this was not possible, participants could afford paying for alternative means of transportation.

It would have been interesting to compare levels of a stress experienced, if the researcher had also been able to access participants from less affluent backgrounds. Lyons (2004) found in her study that experiences of women from less fortunate backgrounds tended to be complicated more by the shortage of resources, thereby imposing greater challenges on these women compared to more affluent women. Further, it would also be interesting to gain an understanding of how single mothers would have also experienced the demands of the illness.

(v) Body Image Perceptions

According to Jade (1999), body image perceptions are made up of the meanings that individuals make of their physical appearance. In arriving at this meaning making process, individuals draw from a number of evaluative sources. The self-discrepancy theory provides excellent guidance for understanding the sources used in evaluating one's body image, through its presentation of the actual self and the idealised self. In this case, the actual self would be the existing physical attributes of an individual while the ideal self would be made up more of the wished for attributes, be it a slimmer body or longer legs for instance.

As various authors have demonstrated, the actual self is indeed who we are, while the ideal self is more abstract and is influenced by a number of factors such as the media and society (Jade 1999; Thorne & Murray, 2000). The Self-discrepancy theory thus tells us that individuals may use these evaluative sources (the media and society) as benchmarks for whether or not they are to be satisfied with their body images, where a perception of dissatisfaction with ones body image yields a discrepancy between the actual and the idealised body image. Generally, one will find that women, and more particularly younger women, often report greater body image dissatisfaction compared to their male counterparts and older women (Muth & Cash, 1997).

The breast cancer experience may therefore add to already existing dissatisfaction with ones body image as it effects a loss of hair in most cases as well as a change in breast size and structure, thus increasing body image dissatisfaction According to Higgins (1997) and Lichtenthal, Cruess, Clark and Ming (2004), the discrepancy between the actual self

and the idealised images of the self with regards to body image, often gives rise to psychological distress.

Results of the current study revealed that the overriding concern with regard to body image perceptions related to the alterations in the breast, whether as a result of a mastectomy or lumpectomy. Even though all the participants indicated that the operation was worth it given that it increased their survival chances, this appreciation was not free of any challenges. Results of the current study clearly indicated that for participants whose whole breast had to be removed, there remained ongoing and immense difficulty adjusting to and living with only one breast. This finding is congruent with Lo Castro's (2003) finding that mastectomy patients often battle with an altered body image. For the participants of this study, the difficulty in this regard centred on the idea of an incomplete feminine identity due to breast removal.

For the participants, the breast was symbolic of feminine sexuality as well as their reproductive capacity, providing a source of sexual stimulation and pleasure as well as being central to breast feeding (maternal significance). It is for this reason that women in the current study experienced and perceived an incomplete feminine identity upon breast removal as has been found by other studies (Lichtenthal et al., 2004). This translated into a perceived decline in attractiveness. Thus participants reported having developed a discomfort with their bodies as well as the perception that they were no longer as attractive to their partners. This difficulty seemed to be a matter of adjustment where participants had difficulty getting used to their altered body image. This adjustment however, appeared to be more manageable for participants who had partners who helped them through the experience. For a participant's whose relationship had already proved

dysfunctional prior to diagnosis, the experience was however aggravated as she perceived it as posing a greater threat to her marriage.

For participants who found themselves single during the breast cancer experience, activities such as dating in future appeared farfetched as a result of their reported difficulty with their body image perceptions. These participants indicated that disclosing and having to reveal a scarred chest area to new intimate partners would not be a pleasant activity and they feared rejection.

Schover (2000) indicates that body image perception disturbances and sexual dissatisfaction is influenced by levels of satisfaction with the intimate relationship before diagnosis and treatment.

An important point to note with the findings on body image perceptions is that social activities that require exclusive couture, for example parties, came across as presenting a challenge for those participants who had gone through breast removal as they felt that it was not possible for them to wear revealing or tight clothing. These participants felt that such clothing would draw attention to the affected chest area thus making them appear different. One participant in particular, ended up avoiding such functions. Social activities such as parties are indeed appropriate to women in the younger age group as this becomes a platform to meet and make new friends and partners and perceptions of attractiveness and health prove somewhat central in the initiation and sustenance of intimate relationships (Jade, 1999, Lo Castro, 2003, and Schover, 1994).

Seeing that this study was composed of only women of African descent, it may have proved beneficial to explore whether there were any ethnically motivated explanations

for the negative nature of body image perceptions. Results of a study by Van Oers' (1996) which involved African women, revealed greater dissatisfaction with body image in African women who had breast cancer as compared to White women. The only difficulty is that these findings focused more on weight loss, maintaining that the reason for a negative experience had been that amongst the African population, weight loss is seen in a negative light that can only indicate extreme illness.

(v) Appreciation of Life

Malandra (n.d.) defines the concept of 'benefit finding' as an ability to see positive things out of a negative situation. Different scholars have conceptualised 'benefit finding' in various ways. For instance, Tedeschi, Park and Calhoun (1998) regard it as a coping strategy while Taylor, Wood and Litchman (1983) see it as a personality characteristic. McAdams (1993); Mcadams, Reynolds, Lewis, Patten and Bowman (2001), on the other hand, regard it as a personality trait. Despite the lack of consensus with regards to what psychological attribute 'benefit finding' is, there is however an agreement that patients' experiences of 'benefit finding' during times of illness contributes to their psychological and physical health. This has been found to be particularly the case for patients with breast cancer, HIV/AIDS as well as multiple sclerosis (Malandra, not dated).

Despite the breast cancer experience having brought challenges into all participants' lives, there were however, participants reported that it did increase their appreciation of life. They reported that with the experience came a realisation that their lives were worth more than they had previously realised and thus they needed to appreciate their health and vitality. Some of the participants reported now seeing themselves as individuals

destined for growth and excellence in all they set out to achieve. Such increased appreciation of life has helped participants view themselves in a better light, plan and look forward to realising their dreams more than they previously had done.

Results of the current study are consistent with those of Lechner, Zakowski, Antoni, Greenhawt, Block and Block (2003) who found that younger cancer patients report more 'benefit finding' from the experience than older patients. Being experienced early in life gave them yet another chance in life.

5.3. SOCIAL SEQUELAE OF BREAST CANCER

(i) The Partner Relationship and Sexuality

The intimate partner relationship plays a crucial role in recovery during the breast cancer experience. It has been established that despite the availability of other helping relationships, perceptions of dissatisfaction with the intimate partner relationship can have adverse effects on the concerned woman's psychological response and adjustment to the cancer (Baider, Andritsch, Goldzweig, Uzielt, Ever-Hadani, Hofman, Krenn & Samonigg, 2004; Coyne & Anderson 1999; Pistrang & Barker, 1995). Thus depending on how well the couple is coping with the cancer; intimate relationships can either be a source of stress or support (Ben- Zur, 2001; Northouse, Templin & Mood, 2001).

It is important to note that the role of the intimate relationship does not however, only become important during the breast cancer experience. It has been established that its functioning prior to the breast cancer experience plays a crucial role in patient's

psychosocial and psychosexual adjustment during and after diagnosis and treatment (Holmberg, Scott, Alexy & Fife, 2001). A positive partner helping relationship would ideally be one composed of high levels of empathy as well as low withdrawal from the male partner's side (Pistrang & Barker, 1995). A negative partner relationship would on the other hand be one characterised by little communication, understanding and support.

Maguire (1981) clearly pointed out that in looking at the intimate partner relationship's adjustment, it is important to note that situations may arise where the male partner is facing extreme psychological distress as a result of the process, thus posing a threat to the intimate partner relationship. Other research has also indicated that the discrepancy between the male and female partner's perceptions of the needed support may also present difficulty, particularly where such expectations are not communicated (Baider, et al., 2004).

Participants in the current study reported the effects that the experience had on their intimate relationships as follows:

1. Disruption in sexual activity
2. Shifting of responsibilities to male partners.

Such disruptions and adjustments were reported to have been due to factors such as pains and complications brought about by treatment side effects, for instance, physical immobility, vaginal dryness as well as loss of libido. It was not however, only the physical side effects that impacted negatively on the intimate relationship and particularly sexual activity. Participants' body image perceptions also impacted on sexual activity, as

female partners reported initially feeling uncomfortable with their changed appearance and therefore engaging in sexual activity.

These findings are in agreement with Breast Cancer Care's (2004) report that part of the breast cancer experience aftermath involves women's experience of a change in the way they feel about or experience their sexual lives as a result of the physical and emotional effects of a changed body image following operation. Linked to the physical impact of breast cancer therefore, is the challenge of adjustment to changes in body image. This change has been found to often impact negatively on perceptions of womanhood, attractiveness and sexual desirability because the breast is in essence, one of the most explicit biological and social symbols of womanhood (Schover, 1997).

Despite a disruption in sexual activity, results of the current study suggest that intimacy did not necessarily fade away as it surfaced that, for some of the participants, the experience served to strengthen participant's relationships, bringing them closer to their partners. This was the case for four participants in the study, including the two participants that lost their partners during the experience. This is consistent with reports by Holmeberg (2001) and Skerret, (2003) that optimal functioning during the breast cancer experience relies largely on couples managing to see the experience as both their problem, not only one partner's. Such a perception of the challenge would be one where couples' closeness allows them seek and find strength in each other.

It was noticed from participant's stories that the illness was indeed a "we" experience where couples instituted and implemented plans to cope. Activities such as going to hospital together brought couples even closer to each other. It also came across that these

relationships had been functioning optimally prior to the diagnosis and hence such experiences did not, lead to relationship disintegration nor were there any extramarital affairs reported. The one participant, whose intimate relationship was experiencing difficulties, did not have a good relationship prior to the diagnosis of cancer. This suggests that for an already ill-adjusted relationship, there exists greater room for the breast cancer experience to worsen an already negative experience of ones intimate relationship, should the couple not work at improving their situation. This finding concurs with that of Taylor-Brown, Kilpatrick, Maunsell and Dorval (2000) who assert that not all couples respond the same way to the breast cancer experience and that pre-existing problems such, as a lack of communication, difficulty with conflict resolution, substance abuse, prior infidelity and or abuse in the relationship are risk factors for a relationship breakdown once the cancer has being diagnosed and the patient undergoes treatment. These findings contrast with findings from a study by Silver (2004), who reports partners leaving merely due to the adverse effects brought about by the cancer.

(ii) The Mother-Child-Relationship

According to the American Cancer Society (1993), more than 30 percent of women diagnosed with breast cancer at any time will be in their child-rearing years. This was indeed true for the majority of the women in the current study as they either already had children of their own, had taken on the role of adoptive parents or were planning conceiving for the first time or having more children. All children of participants in the current study were still young (with the youngest being delivered shortly after mother's

diagnosis and the oldest being in the preadolescent stage).

Having young children is amongst the factors that Avis, Crawford and Manuel (2005) found to have caused distress for women of younger age as the process disrupted the mother-child relationship. Women in the current study reported temporary and relative disruption in the mother-child relationship. This was reported to have been due to the fact that actively taking care of children during the breast cancer experience was affected as a result of physical difficulty. Mothers therefore had to delegate childcare activities to partners, family members and relatives. Sadness and guilt emerged as prominent feelings in relation to their inability to be fully there for their children, particularly as the majority of them had young children who needed much taking care of.

Participants also reported that their illness made their children sad as a result of witnessing their mothers go through pain and at times through physical immobility. According to Lewis, Hammond and Woods (1992) at the time of diagnosis and treatment, routine ways of relating to the parent may be altered by the parent's illness and this may often result in distress and confusion in children. In this study, the one participant who took the opportunity to communicate to her children that she had cancer, what it was, how long she would be admitted in hospital and allowed them to see and feel her breast maintained that this act reduced worry in her children as they felt involved and more or less knew what to expect, allowing them to also talk openly about the cancer, just as their mother had done. This suggests that the act of mothers, fathers, counsellors or physicians taking the opportunity to communicate with the children about the illness could be beneficial in alleviating feelings of anxiety and depression and improving children's coping with the process.

It is worth noting that four of the participants in the current study were mothers who were in better-adjusted relationships (three of them married and one in a cohabiting relationship), which allowed more frequent exchange with their children thus opening the channel of communicating through fathers. Hence mothers' reports that despite the negative experiences, their children were not however, at any point neglected.

(ii) Social Networks: Friends and Extended Families

Immediate and extended families of participants were reported to have provided both practical as well as emotional forms of support although this support faced challenges at times. For instance, each of the participants' families had been through some kind of stressor, particularly related to loss. Participant's illness thus provoked anxiety and depressed mood and put strain on families' coping in light of prior experiences of loss. Adjustment difficulties experienced by families were thus reported to have led participants to feeling as though they were burdening their families emotionally as well as financially.

Social networks in the form of friends, colleagues, and fellow church members were reported to have been experienced in differing ways. Firstly, most individuals within participants' social networks were reported to have provided both practical and emotional support through for instance helping out in the house, offering to drive or accompany participants where necessary and also through offering prayers. Bloom et al. (2001) indicates that the availability of such forms of support and not necessarily their use often contributes largely to buffering against patients' experiences of stress and therefore contributes to improving patients' physical and psychological health.

On the other hand some of the relationships within participants' social networks, especially those with colleagues and friends (excluding fellow church members) were reported to have been confused, strained and tested as a result of the illness. Despite such individuals appearing as sources of support for all participants, it did however emerge, that participants could not rely heavily on such individuals as some of them did not understand the nature of the illness or were angry about participants' having to increasingly take time off work. Such relationships were also contaminated by these individuals' assumptions that participants were HIV positive and were using breast cancer to conceal the real diagnosis (see HIV/ AIDS discussion for details). As mentioned previously, partner relationships played a significant role with regards to support hence perhaps the effects of the threat to social networks may have been reduced by the availability of partner relationships and other sources of support such as the church.

5.4. OTHER EMERGING THEMES

This section of the discussion aims to give the reader insight into other themes that emerged and were prominent across cases despite having not been involved in the interview schedule.

(i) HIV/AIDS

Confusion and disbelief amongst people within participants' social networks as to the nature of the illness was reported by three participants in the current study. These participants reported that friends and colleagues assumed that the participants were in fact

HIV positive and were merely using breast cancer to hide the real diagnosis. For participants for whom this was the case, hurt feelings surfaced in relation to these misconceptions. This misconception also evidently threatened participants' perceptions of support offered by such individuals as they could not fully understand the source of such misperceptions as well as whether or not support or kind wishes offered were indeed genuine.

(ii) Religion as a Coping Mechanism

Despite being often neglected in clinical settings, research has increasingly documented the use of religion and particularly that of prayer as providing a source of strength and hope and at times as an explanatory model during times of ill health (Aukst-Margeti & Margeti, 2005). In contrast to spirituality which is a much broader and diverse concept, religion is more specific as it can be linked to the degree of involvement of a religious grouping. Participants in the current study reported having utilised their religious orientation as a source of coping, hope and as an explanatory model. Being Christian, participants in the current study reported having often asked God questions such as why they had to be the ones falling sick. They also asked God for better health and reported having later expressed their gratitude for health and life after the breast cancer experience, maintaining that they believed God had plans for them and that they were grateful that part of the plan consisted of a second chance at life.

Thus prayer, whether alone or with others marked an integral part of the illness experience. Raji (2004) defines prayer as an earnest activity aimed at either requesting or thanking God or some object of worship for something received or wished for. The

importance of religion in this study did not only have to do with communication with the omnipotent but also involved fellow church members as a source of great support, thus helping participants find strength and reaffirming God's strength during their time of adversity.

Findings of the current study with regards to religion were in agreement with Aukst-Margeti & Margeti (2005) and Raji (2004) that religion can impact health in following ways:

- 1) By providing a framework to for coping with and the reduction of the stress brought about by difficult situations in life
- 2) By opening up channels for social support.
- 3) By promoting healthier living habits.

This then clearly highlights that for religiously oriented patients, the practices and beliefs associated with their religion can be potentially health enhancing, having the potential to impact significantly on physical as well as psychological health outcomes through the restoration of hope and opposing counteracting hopelessness. This therefore clearly highlights the need for clinicians or health care workers to capitalize on patients' religious coping mechanisms through supporting patients' religious practices if they so inclined.

(iii)Physical Health Outcomes

Experiences of two participants in the current highlighted the critical role that psychosocial factors may play in influencing the illness experience as well as physical health outcomes. Experiences of these two participants involved mainly the loss of loved ones during the breast cancer experience thus opening up a gap in terms of participant's coping resources at this challenging time in their lives. For one participant, the loss was coupled with her perception of being vulnerable as well as the anticipated impending possibility of an inability to fulfill her family responsibilities. Both these participants reported having experienced extreme side effects as well as two recurrences. Compared to the rest of the participants, they faced extremely adverse psychosocial adjustment demands that required their attention simultaneously with the cancer.

For one of these participants, the impact of adversity on her health was reported to have been directly linked as she reported having started experiencing immense side effects such a drop in blood cells, only following losing her partner, despite having not experienced these before. Research has increasingly ascertained the crucial role played by psychosocial factors such as coping, family and intimate relationships in influencing health outcomes (Bleiker, Pouwer, Van der Ploeg, Leer & Ader, 1999; Forsen, 1990). It emerged from interviews with participants that the experiencing of intense psychosocial difficulty, was highly likely to have contributed to poor physical health outcomes amongst participants going through such difficulties. This finding is in line with results of a study by Pistrang and Barker (1995) which revealed that positive and nurturing close relationships contribute significantly to alleviating the stress brought about by the breast cancer

experience thus enabling patients to better cope with the illness. In the aforementioned participant's lives, the most solid sources of supported were lost suddenly thus unexpectedly shattering participant's coping and reminding them of their own vulnerability during a time where they were already battling thoughts around death.

CHAPTER 6

CONCLUSION AND RECOMMENDATIONS

6.1. Introduction

The aim of the study was that of gaining insight into younger women's experiences of breast cancer, in relation to how the diagnostic and treatment process impacted on their psychosocial worlds, especially as women of younger age. To achieve this aim, a semi-structured interview schedule was designed in line with the themes that the review of literature revealed as often being of significance during the breast cancer experience, specifically in younger women. In order to in order to develop an understanding of the factors contributing to the study's findings, the biopsychosocial as well as epigenetic theories were utilised as theoretical frameworks informing the study. These two theories proved relevant for the study through their consideration of the interaction of contextual factors in influencing life experiences such as illness.

The main assumption of the biopsychosocial model is that ill health and well being are aspects of not only physical but of social as well as psychological concern. Through this assumption the theory thus presents that social and psychological factors play an influential role in affecting and influencing the onset, manifestation and experience of illness. Drawing from the biopsychosocial model, the current study therefore looked at how the breast cancer diagnosis and treatment processes impacted on younger women's psychological and social worlds, seeking also to understand how the impact imposed by

the cancer on psychosocial well being may have in turn influenced their experience of the illness and its outcomes.

The second theoretical perspective employed in this study was that of Erik Erikson's epigenetic principle. The use of this theory sought to facilitate the researcher's understanding on how the diagnosis and treatment of breast cancer marks a unique experience for younger women in relation to their developmental stage and tasks relevant to this stage.

Results of the current study were in line with or confirmed assumptions of the aforementioned theories. As can be seen in the discussion (see Chapter 5 for a detailed discussion), indeed breast cancer diagnosis and treatment processes posed a challenge to participants' psychological and social functioning. The illness brought on perceptions of vulnerability and uncertainty thus evoking feelings of depression as well as anxiety with regards to its possible terminal nature and the implications thereof for the participants and their loved ones. For some the illness brought on recollections of already lived- through experiences of loss.

The illness also called for immediate adjustment in routine functioning, while simultaneously demanding more time and energy than participants could afford, thereby leading participants to feeling overwhelmed and unable to cope. Despite the availability of support from loved ones, in essence, the illness did evoke stress. The physical changes resulting from surgery called for an adjustment in participants' perceptions of their bodies

including attractiveness and femininity. This adjustment process proved incalculably difficult for some of the participants.

All this happened in the midst of participants' being in the developmental stage of young adulthood wherein individuals are concerned with establishing and affirming their identity, establishing a career, developing intimate partner relationships and establishing families (Van Niekerk & Prins 2001). In line with their developmental stage, participants in the current study looked forward to achieving their dreams, had career duties to fulfil and still highly valued their sense of attractiveness and sexuality prior to and during the diagnosis. Tasks relating to family-building, child-bearing and rearing were also important for the participants. All these activities were evidently negatively impacted upon and disrupted to differing extents by the breast cancer experience.

Although some social networks and some participant's intimate relationships were reported to have taken strain as a result of the illness, it did however, emerge that solid family relationships, partner relationships, church relationships as well as religion itself, played a major role in buffering against the negative impact of the illness. Experiences of participants who lost their partners during the breast cancer experience affirmed the role that psychological and social factors can play in influencing health outcomes in patients' lives as witnessed through the immense difficulties faced by these participants following such losses. Faced with the enormous challenge of the illness, participants reported being more appreciative of their lives and their health and vitality.

These findings thus clearly highlighted the interwoven nature of the relationship between biological, social and psychological factors in influencing health outcomes. This therefore affirmed the World Health Organisation's definition of health as not only referring to the absence of disease but also to a state whereby there is complete physical, mental and social well being (Wissing, 1994). And through its portrayal of the impact that the illness experience had on families and social networks, the study's findings are also in line with Schlebusch's (1990) assertion that despite illnesses occurring within individuals, such individuals are however part of a larger system which includes cells, tissues, body organs, family, society as well as religious affiliations. Hence what affects these individuals also has implications for the broader system within which they exist.

6.2. Implications and Recommendations

Results of the study at hand have implications for breast cancer patients, their families, and members of their social networks as well as those involved in health care. Based on these implications, recommendations are made.

There appeared to be increased levels of depression, anxiety or both amongst participants and their loved ones as a result of not being able to fulfil family responsibilities. Being of younger age, patients were concerned about their fertility and had young children, some of whom did not easily adjust to the illness, and who were also reported to have had signs of depressed and anxious mood as a result of uncertainty and lack of information. It emerged that the provision of psycho-education, either in the form of discussions or reading materials to children by one of the mothers helped to keep the children involved

and reduce their anxiety. The provision of such psycho-educational material to families of patients with breast cancer is thus recommended.

Further, this psycho-educational material can even extend to patients' social networks. Social networks such as friends and colleagues can play an important supportive role in patients' lives during times of ill health. However, where there is conflict between work-related duties and responsibilities, this support may be threatened. The same also applies where such individuals do not understand breast cancer as an illness and have misperceptions and prejudiced attitudes on HIV/ AIDS. Psycho-education could therefore prove useful for raising awareness and providing education on the treatment process and its potential of increasing survival chances.

Hearing participants in the current study relate how they drew and continued to draw remarkable strength from their religious affiliation as well as from church members, with whom they share similar religious ideology, made it clear that psychological interventions for women with breast cancer should therefore focus on the broader social context in which the cancer occurs. Attempts should be made to support supportive relationships such as support groups which may be outside of the health sector. Regardless of their nature, patients coping mechanisms need to be mobilised, affirmed and strengthened as sources of support, especially because it was evident in the current study that the sources of support can also take strain thus threatening support provision.

Results of the study also revealed that patients' difficulty adjusting to the illness and its

impact on body image posed a challenge to the partner relationship as a whole. And indeed at times the partner relationship as well as sexuality is disrupted by the experience, specifically the treatment regimen. Partner relationship problems were heightened in one particular relationship where there was an already existing difficulty in the partner relationship. Body image perceptions and coping with body alterations are indeed a psychological process. Burgess et al. (2005) revealed that previous psychological treatment had a role to play in experiences of depression and anxiety or both around diagnosis. Despite the lack of information on the current study's participant's prior psychological functioning, this assertion however, prompts the recommendation for a holistic situational assessment of patient's prior psychological functioning so as to keep track of their weak points as well as reinforce their strong psychological attributes, which may include prior or current satisfaction or dissatisfaction with their body image. Such understanding of participants' functioning could assist health care provision from a counselling perspective through giving direction as to the issues that the counselling process would need to focus on.

The findings of this study therefore suggest the need for health care services to provide inclusive holistic dedicated health care during this time. In addition to the physical treatment of breast cancer, interventions should also include psychological counselling and support for the actual patient as well as psycho-education of families, friends and colleagues so as to ensure a supportive social context.

6.3. Limitations and Recommendations for Further Research

The current study was limited in that the participants were all of African descent and were from affluent urban backgrounds. Although these women's involvement provided rich insight, it did however prove to limit the understanding that could have been gained through the participation of a more diverse group with regards to the aforementioned factors, thus limiting our understanding of the experiences of younger women from other backgrounds. In particular, it would be interesting to have developed an understanding of the experiences of rural women with low educational levels as well as experiences of women of other racial backgrounds in South Africa.

Investigations should therefore be made into the experiences of younger rural women, inquiring into incidence and adjustment. Their remoteness to health care facilities, lack of education and finances may imply poor prognosis for these women. It may also prove interesting and beneficial to explore whether patients may at any point employ cultural explanations for the cancer.

A further limitation of the study was the lack of a psychological history on the participants. For instance, having an understanding of participants' prior psychological functioning could have gone a long way in putting findings such as depressed and anxious mood into context. Thus further research could follow the direction of seeking to solicit histories on prior social and psychological functioning. Such insights could assist those involved in health care during intervention as they would facilitate better contextual understandings of patients' experiences and difficulties.

APPENDICE A: CONSENT FORM

University of KwaZulu-Natal

Howard College Campus

Durban

4041

MINI-DISSERTATION: AN INVESTIGATION INTO YOUNGER WOMEN'S EXPERIENCES OF THE PSYCHOSOCIAL IMPACT OF BREAST CANCER: DIAGNOSIS, TREATMENT AND BEYOND.

CONSENT TO PARTICIPATE IN RESEARCH

Dear participant we are asking you to participate in this research so that we could inquire into your experiences of the psychosocial impact of breast cancer through the stages of diagnosis, treatment and survival.

This research will be conducted by S'thembile "Nonto" Mjadu and supervised by Professor Inge Petersen.

If you agree to participate in this study, you will respond to questions regarding your experiences of the psychosocial impact of breast cancer in your life.

By agreeing to participate, you will be contributing to the advancement of knowledge of the issues experienced by women who have been diagnosed with breast cancer. Please be informed that your participation is confidential and the publication will be anonymous, only summarising the information and not involving your name or any other information directly and explicitly linking the research to you.

If you decide to participate, you are free to withdraw at any stage in the process.

If you need to ask questions about the study, S'thembile Mjadu is available on 076 04 38559.

If you sign your name below it means you are agreeing to participate in this study.

I _____, agree to participate in this study exploring younger women's experiences of the psychosocial impact of breast cancer. I am fully aware of: the nature of the research, that my participation is voluntary, confidentiality and that should I wish to withdraw from the study, at any time, I have the right to do so. I can call S'thembile "Nonto" Mjadu on 076 043 8559.

Signature

Date

APPENDICE B: SEMI-STRUCTURED INTERVIEW GUIDE

Thank you for availing yourself to participate in this study. The study is concerned with understanding the challenges that breast cancer brings about for diagnosed women's social and psychological worlds. The study focuses on understanding issues specific to younger women like you. Today you will be asked questions relating to this. Your openness and honesty will be highly appreciated.

BACKGROUND

1. Please shed some light on how you discovered the cancer.
2. What was the experience like biologically and medically?

SOCIAL

3. How were the reactions of those close to you, such as your partner, children, friends, colleagues and family members?
4. If you have children, how did your child/ children adjust and live with your diagnosis and having to undergo continuous treatment appointments, procedures and sometimes side effects?
5. How did you go about maintaining the relationship between yourself and your child/children as well as the responsibilities of being a mother?

6. If you did have a partner at the time of diagnosis, how did they receive the news of your diagnosis?
7. How has your partner adjusted to the process?
8. Would you kindly reflect on your sexual relations following the diagnosis?
9. And how have your social networks (friends and colleagues) been since the diagnosis in terms of prior relations and support?

PSYCHOLOGICAL

10. How have you been experiencing your body and its appearance in relation to the diagnosis and treatment procedures that have followed (like the operation)?
11. How would you say the diagnosis has impacted or influenced if it has, the way you see and define yourself?
12. How has the diagnosis and treatment affected you emotionally? (Probe for depression and anxiety).
13. If you have any other challenges that you feel were brought about by the process, could you kindly shed some light in that regard.
14. Do you have any questions or comments?

Thank you for your participation.

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