

A microsociological analysis of social support to women diagnosed with early stage breast cancer.

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Keywords

Microsociological, analysis, family, social support, women, early stage breast cancer, South Africa



Abstract

This study explored the social support provided by family of women diagnosed with early stage breast cancer.

The aim was to present an account of social support that is solicited by and given to women diagnosed with early stage breast cancer. There is a dearth amount of literature on support from families of women with breast cancer in South Africa. Thus, this study can potentially contribute to filling the gap of knowledge in this area in the country.

Qualitative method was used and in-depth interviews were utilized to study the women's experience of family social support. The theoretical framework underpinning the study is the relational communicational perspective.



Declaration

I declare that A Microsociological analysis of social support to women diagnosed with early stage breast cancer is my own work, that it has not been submitted before for any degree or examination in any other university, and that all the sources I have used or quoted have been acknowledged as complete references.

Thembekile Nokukhanya Kamanga

November 2016

Signed:



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Chapter One: Introduction

1. Introduction

Breast cancer is a growing health issue for women worldwide. Although men also get breast cancer, it is the most frequently diagnosed in females (Jemal, Bray, Center, Ferlay, Ward & Forman, 2011). In 2008, the estimated breast cancer cases affecting females globally was 1 383 500 (Jemal *et al*, 2011). Retrieving accurate statistics for incidence and death rates is difficult in economically developing countries because cancer registries are non-existent and/or limited and death registrations are not comprehensive enough. However, the little information available is used, to estimate the incidence and mortality for these countries (Jemal *et al*, 2011). The breast cancer statistics for South Africa in 2008 for all females was 23.29 cases per 100 000 (National Health Laboratory Service, 2015).

Breast cancer is a term that refers to “*an uncontrolled malignancy or cell growth [in the breast]*” (Bahar, 2003:1026). The malignancy or cell growth has the potential to “*invade normal tissue and spread to other parts of the body*” (Bahar, 2003:1026). South Africa’s number one leading cancer for women is breast cancer. The cancer seems to affect black and white women in South Africa differently and 1 in 81 black women are at risk of developing breast cancer in their lifetime, in contrast, white women have a 1 in 13 lifetime risk (Vorobiof, Sitas and Vorobiof, 2001:125s). The lifetime risk of developing breast cancer is also different amongst rural versus urban living blacks. There are varieties of factors that are said to contribute to this.

Breast cancer is a disease that can be cured, however this sometimes depends on the stage of the cancer, and whether or not it has spread to other parts of the body. There is a risk of recurrence, hence the need for regular check-ups.

As the incidence of cancer increases, more families are being exposed to and/or experience the hardships of the cancer journey. Thus, more families have to learn how to deal with the difficulties that cancer can bring. One of the ways that families can help women with breast cancer is by offering social support. This study examines the

types of social support available to women who have been diagnosed with breast cancer. The different types of the support are explained later in the chapter. A qualitative methodology and the phenomenological approach, which is both descriptive and interpretive, was used to obtain the views of a sample of ten (10) women, living in Cape Town, who were diagnosed with breast cancer. A semi-structured, open-ended questionnaire was used during the interviews. In addition, the observations made and the conversations with women at support group meetings, is included in the findings.

The study asks questions such as: whom do women turn to within the family for assistance? Do they have to ask for their support? What type of support are they looking for and from whom within the family? How beneficial do they find the support various family participants?

Formerly, it was mentioned that a breast cancer diagnosis could bring about significant distress of a psychological, sociological (biographical disruption) and economical nature. Social support can thus play a significant positive role in decreasing the effects of these distresses. One uses ‘can’ as it will be shown in the literature section and in the findings, that the recipients do not deem all forms of support positive. The specifics of the type of support, and whom it comes from, are also factors to be considered.

1.2 Background

A chronic illness such as breast cancer is “[an] experience where the structures of everyday life and the forms of knowledge [that] underpin them are disrupted” (Bury, 1982: 169). The diagnosis of breast cancer also brings to the forefront awareness “of the worlds of pain and suffering, possibly even death, which are normally seen as distant possibilities or the plight of others” (Bury, 1982:169). Additionally, the breast cancer patients, their families and wider’ social networks are coerced to face the truth of the character of their relationships, which disrupts normal rules of reciprocity and mutual support (Bury, 1982: 169). In other words, breast cancer does not only disrupt the biography of the patient, social relationships are affected as well.

To expand on this, the illness and treatment of breast cancer causes the body to have unpredictable demands, which majority of the time influence how the patient will live their day-to-day lives, and how engagement will occur in personal relationships (Radley, 1989: 232). When one is diagnosed with an illness such as breast cancer the body is not only an inhabitant of that disease, it is *“that through which one continues to apprehend the world and oneself in it”* (Radley, 1989: 232). The beginning of an illness such as breast cancer can be seen as the start of change for the relationship between the patient and society and between the patient and her bodily condition (William, 1984 cited in Radley, 1989: 233). As a breast cancer patient’s illness journey progresses, it is no longer a disease that merely exists; it becomes a part of the patient’s *“conduct through their attempts to combat or to adjust to its demands”* (Radley, 1989: 233).

The combating or adjusting to the demands of the illness that the patient has to do, is not the same for all breast cancer patients as their *“social and bodily circumstances are not identical”* (Radley, 1989:233). Adjustment to illness is a process that involves *“people making sense of their situation, giving meaning to painful and sometimes frightening experiences and legitimizing their ways of coping in the eyes of other people”* (Radley, 1989: 234). These experiences are signified and justified through communication with others about what they are doing to deal with their illness (Radley, 1989: 234).

When one is diagnosed with a breast cancer a wide variety of fears may emerge at diagnosis, during the treatment phase, and after one has survived it. These fears include; *“fear of pain and suffering, fear of disfigurement by the removal of body parts, fears of costs for care, fear of losing work, family and friends, fear of dependency, [fear of recurrence] and fear of death”* (Schulz and Mohamed, 2004: 653). As much as there may be stress and anxiety during the tackling of breast cancer; women can have some positive outcomes and changes occurring in the respective spheres in their lives. There have been reports where cancer patients have said that the cancer assisted in creating a deeper bond in social relationships with friends and family. In these instances, individuals had a new approach to life and new priorities that possibly influenced their daily activities (Schulz and Mohamed, 2004: 653).

1.3 Definitions of Social support:

There are various definitions for social support and one does notice similarities in most of them. These will be briefly discussed below. Firstly, the structure of social support is comprised of instrumental, emotional and informational support (Then, 1997). This suggests that there are different aspects and “*the strength of the direct effect of social support on psychological well-being and mental health may vary depending on the types of supportive functions measured*” (Theun, 1997: 104). These components are at times seen individually, but they can also be seen as inter-related because, “*help-giving interactions, esteem enhancing behaviours and advice-giving typically occur together and are frequently derived from the same sources*” (Theun, 1997: 104).

Coyne and DeLongis (1986: 454) describe social support as “*complex, reciprocal and contingent*” (cited in McColl, 1996: 396). Another scholar, who takes a similar approach to Coyne and DeLongis, is Morgan (1989), who is of the view that social support, as a social exchange, is limiting. According to Morgan, the reason for this relates to the nature of a supportive relationship, which is reciprocal, and has to be interpreted more broadly (McColl *et al*, 1995: 396). Gottlieb and Bergen (2009: 512) have defined social support as the social resources that persons, “*perceive to be available or that are actually provided to them by non-professionals in the context of both formal support groups and informal helping relationships*”. Sarason, Levine, Basham and Sarason, (1983: 127) defined it as the “*existence or availability of people on who we can rely, people who let us know that they care about, value and love us*”.

In summation, currently there is no agreed upon definition for social support. It is composed of three components, instrumental, emotional and informational. The type of support that is given by an individual is an important factor, as it could have an effect on the adjustment of the recipients. Furthermore, it can foster a sense of meaning and purpose in life, for individuals inflicted with illness. In the study, I did not want to focus on one specific social support. I was interested in learning about

what the different types of social support that the individuals receive and which they found beneficial.

1.4 Aim and Objectives

A breast cancer diagnosis for a woman can cause significant distress psychologically and socially, as well as for her family. Consequently, the family has to provide support, given the various factors that they have to deal with because of an illness such as breast cancer. In seeking accounts of support from the women one aims to:

-Present an account of social support provided by the families of women diagnosed with early stage breast cancer

-Gain an understanding of what type of support women are receiving. Do they find it beneficial?

-Additionally, is there any other form of support they would want from their families? The findings can be a 'conversation starter' for other families who are faced with the breast cancer journey. This leads to the aim of the research, which was to present an account of the social support provided by the families of women with early stage breast cancer.

The following chapter (Chapter Two) is the literature review. In it, a discussion of international and local studies regarding breast cancer and support takes place. I have tried to be as extensive as possible. Unfortunately, the local research is not as comprehensive as one would have hoped, because of the shortage of studies relating to this subject. Chapter Three outlines the methodology and methods. The phenomenological method and the steps used to gather data are described in this section. The subsequent chapters (Chapters Four and Five) discuss the findings and the conclusions that were derived from the data.

Chapter Two: Literature Review

2.1. Introduction

This chapter reviews the literature that is specific to this study. The overview of the literature is not exhaustive; nevertheless, it does aim to give the reader a proper grounding in the theoretical and empirical studies that have been conducted by various scholars. The chapter begins by discussing the history of breast cancer and the social construction thereof. A presentation of cancer statistics globally and for developing countries follows. Thereafter, South African case studies on breast cancer are highlighted and a brief introduction to the challenges faced and recommendations for improvement is introduced. Lastly, literature concerning the social and spousal support provided to women diagnosed with breast cancer, which is the focus of the study, is considered.

2.2 The history of breast cancer

The current focus of breast cancer as consisting of “*body image, identity and self-worth*” is a result of social constructions that have been passed down through time. As with the notion of ‘survival of the fittest’, the same applies to the constructions that have been able to be carried across generations. Thorne and Murray (2000:143) suggest that, those social constructions that have survived; are influenced by scientists and women of privilege.

Scholars began by looking at the social constructions of breast cancer during the Victorian era. During this era, it was believed that “*women were ruled by their bodies-bodies that were seen as unstable and inherently weak*” (Thorne and Murray, 2000; 146). Despite women being seen as frail and weak and under male care, they were also encouraged to be “*strong, protective and selfless*” (Thorne and Murray, 2000: 146). When a woman was diagnosed with breast cancer she had to remain positive and in control amongst her family given the circumstances.

In the post World War II era one sees breast cancer surgery hidden and made secret. Women were discouraged from sharing that they had had surgery. The breasts were seen as an important aspect of a woman's sexuality and thus not having breasts was seen as something to be embarrassed or ashamed of. Ussher (1989:27, cited in Thorne and Murray, 2000:148) posits that "*women are objectified and dehumanized, represented as sexual: their sole function being to serve man's pleasure*". Evidence of this was found in stories of women who feared that their husbands would not find them attractive since they had surgery.

In the contemporary era the breast cancer problem has been separated into; "*treatment (property of the oncologist), research (medical researchers), fund-raising (cancer charities and the state), support and educational services (cancer charities, and private anguish (the woman with breast cancer and her family and friends)*" (Thorne and Murray, 2000: 150). 'Controlling' the disease is one of the medical profession's aims when it comes to breast cancer. The issue is one finds that the 'control' is being exerted on the women by doctors communicating in medical jargon that they do not understand. Having to comply with undisclosed rules and programmes that encourage women to 'go back to normal' as soon as possible compounds the problem. Women are then urged to go for regular check-ups and donate money for medical research, there are women (who have and have had breast cancer) who feel that this money is not utilized for the kind of research they would like to see happening.

One can see that there are social constructions from the past that influence contemporary society's notions of breast cancer. It has to be noted that this is in the context of white medical professionals, often male who are shaping the social construction. Scholars such as Thorne and Murray (2000) would argue that it is white male medical professionals and (white) women, who are privileged, who contribute to the current social construction of breast cancer. One does not often hear the minority's views, thoughts and experiences. Thorne and Murray (2000) argued that the contemporary social construction of breast cancer; confuses women who are faced with this disease. The focus of the breast cancer does not address the issues that women (who have the disease and have survived the disease) have to face concerning this disease.

2.3. Global and local cancer statistics

Cancer is increasing globally (Jemal, Bray, Center, Ferlay, Ward and Forman, 2011; Ma and Jemal, 2012; Kamangar, Dores and Anderson, 2006). According to Jemal *et al* (2011:69), this is largely influenced by the *“ageing and growth of the world population [as well] as an increasing adoption of cancer-causing behaviours, especially smoking, in economically developing countries.”* Other contributing factors include the age at first pregnancy, menopause and hormonal exposures and early menarche (ibid).

The Globocan (2008) report estimated about 12.7 million cancer cases and 3.7 million cancer deaths, 56% of the cases and 64% of the deaths are said to have occurred in economically developing countries (Jemal *et al*, 2011:69). The most frequently diagnosed cancer for females is breast cancer, 23% of cancer incidences for women are breast cases and 14% of cancer deaths were due to breast cases in 2008 (Jemal *et al*, 2011).

Kamangar, Dores and Anderson (2006: 2137) attribute incidences of cancer to be *“determined by exposure to etiologic factors and individual susceptibility and may be further affected by screening practices, health care access and quality of care”*. The mortality rate *“is influenced by cancer incidence, individual biologic factors, tumour characteristics and stage at diagnosis, and response to available treatment”* (Kamangar, Dores and Anderson, 2006: 2137).

Jemal *et al* (2011:71) report that breast cancer has overtaken cervical cancer as the leading cause of cancer death among women in economically developing countries. They report the statistics as approximately 50% of the breast cancer incidences and 60% of the deaths are said to have occurred in economically developing countries. The researchers point to high incidence rates in Western and Northern Europe, Australia/New Zealand and North America and low incidence rates in Sub-Saharan Africa and Asia (Jemal *et al*, 2011: 74). Jemal *et al* (2011) and Kamangar, Dores and Anderson (2006) attribute the incidence variation to access to adjuvant therapies,

differences in the availability of screening facilities, and differences in ‘reproductive and hormonal factors’.

Kamangar, Dores and Anderson (2006:2144) provide examples from the UK and the US, which suggest that early detection and improved treatment might reduce mortality rates by 25% to 30%. Jemal *et al* (2011:74) agree with this but caution that, in some economically developing countries mammography is not feasible and thus other recommended early detection strategies include vigorous awareness programs of early signs and symptoms (example is teaching women breast self-examination) and clinical breast examination screening.

According to Jemal *et al* (2011:74) the best strategies to reduce the risk of developing breast cancer are, *“maintaining a healthy body weight, increasing physical activity and minimizing alcohol intake are the best available strategies to reduce the risk of developing breast cancer”*.

Smith, Caleffi, Albert, Chen, Duffy, Franceschi and Nyström (2006: S18) emphasise that *“timely diagnosis of symptomatic disease relies on breast health awareness in the potential patient population and in primary health professionals [thus increased breast health awareness] is a key element of interventions at all resource levels”*. According to Smith *et al* (2006) one has to be mindful that a large portion of women who are diagnosed every year are symptomatic at the time of diagnosis and that most women do not have access to mammography screening. Therefore, the goal of early detection should not solely focus on detecting asymptomatic but it should include downsizing the symptomatic breast cancers as well (Smith *et al*, 2006, S18-S19).

Smith *et al* (2006) acknowledge the value of educating women on breast health, but stress that other potential barriers need to be considered, these barriers being the *“social and cultural factors influencing the potential of earlier detection programs”* (2006: S21). It is indicated by Smith *et al* (2006) that using the tools of medical sociology and medical anthropology, allows for opportunities where researchers are evaluating the social factors of why, for example, a group of women who participated

in a clinical breast examination trial and tested positive, refused to be further examined.

Smith *et al* (2006: S22) attribute “*fatalism, inability to act without the husband’s permission, fear of casting stigma on one’s daughter, fear of being ostracized, fear of contagion, reticence, language barriers (example: the absence of a word for cancer in some languages), preference for traditional healers and others*”. These are seen as being some of the barriers to awareness, seeking and obtaining care and positive responses to screening.

As mentioned above, educating women can assist in breaking down some of these barriers. Nonetheless, there also needs to be “*tailored approaches that take into account culture, religion and other factors*” (Smith *et al*, 2006: S22). On that account, these approaches would be aimed at women, medical professionals and community members. The community members may include leaders such as “*rabbis for orthodox Jewish women, sheiks for Muslim women and the men in the women’s lives (especially in patriarchal societies) and/or traditional healers*” (Smith *et al*, 2006).

In summation of the above, Smith *et al* (2006) strongly “*encourage(s) the contribution and perspective of medical anthropology and medical sociology, and the application of these perspectives and methodologies to the understanding of the local situation in assisting to help clarify barriers*”.

van der Merwe, Hamel, Schneider, Apffelstaedt, Wijnen and Foulkes (2012), Matatiele and Van den Heever (2008) and Pillay (2002) all contend that the breast cancer incidence is increasing in South Africa. The increase is occurring for white, black and coloured women. van der Merwe *et al* (2012) report the incidence rate for coloured and black women living in the Western Cape is 25.6 per 100 000 and 14.7 per 100 000 respectively. Additionally, van der Merwe *et al* (2012: 179-180) report the incidence rate for blacks and coloureds living in urban areas is estimated to be 26.6 per 100 000 and 16.3 per 100 000 for those in rural areas.

According to Matatiele and Van den Heever (2008: 69a), doctors in South Africa have also seen an “*alarming increase in the incidence of breast cancer among (<35*

years) black women a group that was previously considered to have the lowest risk of breast cancer". Furthermore the young women who do get breast cancer; are reported, to be "*diagnosed with a more virulent form of the disease*" (Matatiele and Van den Heever, 2008: 69a). In line with the previous statement, (Tum, Maree & Clarke, 2013: 108) indicate that; "*breast cancer in the black population is more advanced at presentation than in other population groups as 77% of patients of all age groups with stage 3 and 4 breast cancer, compared with 30.7 in non-black women*". Pillay (2002:104) states that the lifetime risk for black women is 1 in 81 and for white women 1 in 13. The possible reasons given for the incidence increase in urban blacks and coloureds is an adoption of the western lifestyle. The lifestyle includes a decrease in physical exercise, women having their first child at a later age, shorter duration of breastfeeding, women having fewer children and hormone replacement therapy (van der Merwe et al, 2012).

2.4. Challenges faced, interventions and recommendations for improvement

Although there are figures for incidence and mortality available, Kruger and Apffelstaedt (2007) argue that these are underestimated because of poor reporting and lack of data availability. Snyman (2010) asserts that breast cancer screening is opportunistic and this is due to the lack of systematic population-based breast cancer screening in South Africa (Tum, Maree & Clarke, 2013: 108). This is unfortunate as Pillay (2002:104) states that the "*only recognized and proven risk reduction measure is regular mammograms after the age of 50 years*". However, mammograms are not cost effective for women under the age of 30 years, and this can discount the women who develop cancer at younger age (Pillay, 2002: 104).

Besides the lack of systematic population-based breast cancer screening in South Africa, there is a lack of awareness about the disease in the female population. The lack of awareness contributes to women not performing self-examinations on their breasts and/or seeking medical assistance. According to Matatiele and Van den Heever (2008: 69a), a number of "*South African women generally have limited knowledge of their relative risk of developing breast cancer, of associated risk factors and of the diversity of potential breast cancer-related symptoms*". Older women,

particularly black women, lack the ability to identify cancer symptoms, *“the risk factors associated with breast cancer and their personal risk of developing the disease and [thus] they seek medical assistance late and consequently exhibit a relatively high mortality”* (Matatiele and Van den Heever, 2008: 69a).

In a bid to educate the South African public about breast cancer and the benefits of early detection, the Cancer Association of South Africa (CANSA), together with the Ministry of Health *“have engaged in breast cancer awareness campaigns in partnership with various organisations”* (Matatiele and Van den Heever, 2008: 69a). These campaigns aim to *“increase awareness of early breast cancer detection services among South African women, and especially reduce, if not eliminate, cultural and economic barriers to breast screening services”* (Matatiele and Van den Heever, 2008: 69a).

October has been recognized as breast cancer awareness month in South Africa, Matatiele and Van den Heever (2008:69a) highlight the activities that occur during the month which include:

- Annual health awareness campaigns for public education.
- Early detection and prevention campaigns provide counselling, appointment-making assistance and referrals to screening services. Individuals are informed about health centres offering these services in their vicinity.
- Health exhibitions in the form of health fairs and contests are held, and printed educational materials are always handed out during these activities.

Matatiele and Van den Heever (2008) evaluated the extent of breast cancer awareness and breast cancer screening practices among women in the Free State province. They focused on women who presented with newly diagnosed at one provincial hospital and this study was carried out for one year. It has to be mentioned that the Universitas Hospital was the only hospital (excluding the private hospitals) that had facilities for breast cancer screening.

The participants in the study were asked questions that assessed their *“knowledge, personal attitudes and practices of breast cancer examination and screening”* (Matatiele and Van den Heever, 2008: 69a). The results of the study showed a low

rate of breast self-examination, 70% of the 56 participants had not ever performed breast self-examination. Of the 70%, 41% presented with stage 3 breast cancer (Matatiele and Van den Heever, 2008: 69b). Matatiele and Van den Heever (2008) indicate that the women reported that their medical professionals did not initiate clinical breast examinations. It is argued by the authors that this reflects negatively on the health workers of the Free State province.

Matatiele and Van den Heever (2008) advocate for an education campaign on breast cancer targeted to health professionals and the public of the province. They argue that for countries that have introduced breast cancer screening programs these have assisted in the decline of deaths from breast cancer. For screening programmes to be effective, they have to be used wisely and regularly and this can only happen if women are knowledgeable about breast health.

Pillay (2002) conducted a study, aimed to examine the awareness of issues relating to breast and cervical cancer among urban and rural African women. The study had 70 urban participants from Pietermaritzburg which is a town situated in Kwa-Zulu Natal and 70 rural women from communities in the northern areas of the province. The findings revealed one in five women did not know of breast and cervical disease. One fifth of the sample did not know about the breast self-examination method, the majority of these women were from the rural communities (Pillay, 2002). One third of the sample also did not know about the medical examinations for breast cancer this knowledge was absent for women living in rural communities and Pillay (2002) attributed this to the lack of “knowledge of the disease and sophisticated health technology, most of which is not accessible in rural or disadvantaged communities”. With these findings, Pillay (2002) argues for more awareness about breast and cervical cancer, especially for women in the rural communities. He also indicates that traditional healers should be engaged in promoting early screening in communities they serve as one third of the rural women preferred to consult with healers about breast lumps (Pillay, 2002: 112).

Tum, Maree and Clarke (2013) conducted a study with the objective of developing and piloting an intervention involving a community health worker to create awareness

of cervical and breast cancer, and to facilitate screening uptake in a specific resource poor community in Tshwane. The researchers approached five community members to be Community health workers; the workers underwent training for a period of time before the commencement of data collection. The community health workers had different roles and one whom was trained for cancer prevention was deployed into the field to teach the community, particularly the women, *“what cancer is, what cervical and breast cancer are, the signs for the diseases, the risk factors, prevention and early detection and the treatment of these diseases”* (Tum, Maree & Clarke, 2013:110). The women were also informed about the location of the venue, screening times and the procedures for the screening.

Tum, Maree and Clarke (2013) sample for the study comprised 22 black South African women, who were all younger than 60 years. The majority (70%) who had had breast and cervical screening prior to the study were literate women. All of the participants acknowledged that the health worker informed them of the screening program and motivated them to participate. When the women were asked to recall what they were informed about breast and cervical cancer, a small group could not recollect any information. Tum, Maree & Clarke (2013:112) report that *“less than half of the sample could remember that both cervical and breast cancer affect women, is a growth, their signs, the risk factors and prevention for these diseases”*. It was found that the majority (75%) of the women who could not remember this information were illiterate.

The effectiveness of the community health worker was not clear in the study and the authors did not fully tackle this subject. Tum, Maree and Clarke (2013) express dissatisfaction with the screening participation in the study. The value of the health worker in disseminating information about cervical and breast cancer was unclear as according to Tum, Maree and Clarke (2013: 114) the *“level of knowledge was still low”*. The researchers do not know why the intervention did not improve knowledge and screening participation however, they consider a potential factor to be the issue of disempowered women in South Africa. Maree and Wright (2010) put forth that some women living in paternalistic societies in South Africa are disempowered and thus they still have to ask for permission for things such as seeking health care. Social support and social influence was another hypothesis brought into discussion by Tum,

Maree and Clarke (2013), the social support from the community health worker proved not to be enough to influence a change in the health behaviours of the women and to encourage greater participation in the screening programme.

2.5. Breast cancer, social and spousal support

A diagnosis of breast cancer can bring about psychosocial challenges for the patient. The diagnosis has the possibility of affecting the mental health of the patients, Hasson-Ohayon, Goldzweig, Braun and Galinsky, (2010:1195) report a third of women diagnosed with the cancer “*suffer from significant distress and problems in psychological functioning*”. Scott, Halford and Ward (2004: 1122) indicate initial reactions to the diagnosis that some women can experience are “*shock, impaired concentration, emotional numbness, insomnia and nightmares, heightened arousal, depression, anxiety and intrusive thoughts about dying or recurrence*”.

Breast cancer and its treatment can also cause sexual difficulties for the patients. Sexual dysfunction has been found in 21-39% of breast cancer patients; it is defined by “*decreased sexual interest, reduced frequency of intercourse and difficulties with orgasm*” (O’Mahoney and Carroll, 1997: 401). There are many contributing elements to causes of sexual dysfunction such as the physiological side effects of the cancer treatment, lower libido and tenderness, the psychological factors brought about by facing a life threatening illness and physical changes of the body. The psychological factors also include anxiety and depression that can affect both the woman and her partner. According to O’Mahoney and Carroll (1997:401), conflict within the relationship may cause an increase in sexual avoidance and difficulties. The distress that women experience may vary during the cancer journey which consists of diagnosis, “*surgical intervention, medical treatment, regular check-ups and fear of recurrence*” (Ben-Zur, Gilbar & Lev, 2001:32).

The couple has to face the challenges that come with breast cancer and thus there is an increased risk for troubled communication and avoidance of conflictual feelings, particularly if open communication has not been a trend in the relationship. These communication problems may increase the emotional distance among the couple and

result in fewer expressions of sexual intimacy (O'Mahoney & Carroll, 1997:402). Scott, Halford and Ward (2004:1122), highlight that approximately 30% of women who have had surgery for breast cancer still struggle with sexual dysfunction and body image problems after many years.

With regards to the social, women find the roles in their intimate relationships and/or families changing. There are women who find this change challenging as Baider and Bengel, (2001:117) argue that, *“traditional gender role socialization and physiological factors encourage women not only to attend to their own health but also to nurture and be attentive to the needs of others”*. Marital theory discussed by O'Mahoney and Carroll (1997: 402) *“individuals develop specific role expectations for their spouses within marriage which contribute a sense of equilibrium and positive marital adjustment”*. O'Mahoney and Carroll (1997:402) add that a change in family dynamics has the potential to cause role strain and this is due to an inconsistency of understanding of expectations for the new roles and the individual's ability to perform them. Furthermore, Baider and Bengel (2001:120) assert that women's perception and construction of social reality differs from men. The core of the difference is influenced by *“experiences of attachment and separation emerging from a perspective of an ‘ethic of care’”* (Baider & Bengel (2001:120). Women assume a disproportionate share of responsibility for maintaining the family organization and providing nurture, this is also true for when they adopt the roles of patient or carer. Women tend to socialize into caretaking roles in close relationships and are more responsive than men to the well being of others, often at severe cost to their own emotional stability.

When individuals are faced with challenges in their lives; they draw upon various resources around them to aid them in coping. These include *“finances, social support, education, intelligence and personality disposition”* (Ben-Zur, Gilbar & Lev, 2001:32). Janoff-Bulman (1992; Manne *et al*, 2007:381) state that a diagnosis of breast cancer may cause one to reconsider their subjective views about the world and oneself, the ability to *“alter one's views and/or goals so that the experience is no longer incongruent with pre-existing views man be dependent on successful adaptation to the illness”*.

Dukes Holland and Holahan (2003:16) claim one of the key elements that aids in the adjustment to cancer is social support. There are many types of support that can be provided to women such as emotional, informational and tangible however the type of support and from who are important factors that have to be considered.

Durkheim (1951) believed “*interpersonal relations between individuals [have] critical consequences for people’s health*” (Cited in Bloom, Stewart, Johnston, Banks & Fobair, 2001). Numerous studies have shown the importance of spousal support for women diagnosed with breast cancer; the studies also show that the spouse’s support is needed throughout the cancer journey (Bloom, 1986; Dunkel-Schetter, 1984; Primono, Yates & Woods, 1990). Studies have also shown that a majority of women tend to turn to the partners/spouses as their main sources of support during the cancer journey (Lethborg, Kissane & Burns, 2003: 64-65). Harris (1978) found that “*supportive relationships with immediate family members did not make up for the lack of spousal support in terms of vulnerability to depression*” (cited in Dehle, Larsen & Landers, 2001: 308).

Bolger, Foster, Vinokur & Ng (1996) state further that it has to be noted that the type of support provided by spouses’ can positively or negatively affect the patient’s adjustment process. Manne, Ostoff, Winkel, Fox, Grana, Miller and Frazier (2004: 661) continue in agreement with the previous statement by asserting that, “*theoretical perspectives on social support and intimacy overwhelmingly suggest that effective and supportive responses are characterized by expressions of acceptance, nurturance, validation and/or empathy*”.

A strong predictor of the patient’s mood and quality of life is the satisfaction felt with their spouses’ provision of support. Women have reported feeling content when their spouses expressed affection, and empathy during discussions related to cancer. Scott, Halford and Ward (2004:1123) found the responses from spouses that women viewed as unsupportive were “*avoiding cancer related discussions, withdrawing emotionally, minimizing the impact of the cancer and criticizing how they were coping*”. Gremore, Baucom, Porter, Kirby, Atkins and Keefe (2011:21) gave an account of how other women have reported “*unsupportive behaviours that include minimizing the problem,*

forced cheerfulness and insensitive comments”, this has led some women to report their spouse as insensitive and patronizing. These negative responses can become social constraints on disclosure for the patients. Social constraints have been defined by Pasipanodya, Parrish, Laurenceau, Cohen, Siegel, Graber and Belcher (2012: 662) as “*interpersonal factors that limit an individual’s willingness or ability to communicate with others*”. The words spoken by the spouse and/or indirect or direct actions can affect patients by causing them to withhold communication concerning their feelings or concerns and thoughts about a matter that they interpret as stressful (Pasipanodya *et al*, 2012: 662).

Providing spousal support can be complex as; Scott, Halford and Ward (2004) have suggested, women who are adjusting better and positively to their breast cancer might increase the likelihood of their partners’ providing support and women who show signs of constraint distress and poor adjustment may cause their partners to withdraw from them and exhibit negativity. Pistrang and Barker (1992) have reported that patients can be direct and indirect in their elicitation of support however a key strategy that has been identified in context of dealing with cancer is the disclosure of worries and concerns to the spouse (Manne *et al*, 2004: 661).

Relational perspective reason that a woman’s adaptation to breast cancer may be enhanced by close interpersonal relations (Zunkel, 2003:41). The following are various studies that have looked at support provided by spouses to women who have been diagnosed with breast cancer.

Dukes Holland and Holahan (2003) conducted a study looking at the relation of social support and coping to positive adaptation to breast cancer. The results revealed that perception of social support for the women with breast cancer; positively influenced their adjustment to the illness. Additionally, the women also practiced positive health behaviours. Dukes Holland and Holahan (2003:25) found the perceived social support seemed to correlate with women adopting ‘approach coping strategies’ however there was no relation between social support and avoidance coping strategies. In other words, women who perceived the availability of social support were more likely to adopt a coping strategy that was beneficial to their cancer journey but there was no

direct relation between social support and women who adopted avoidant coping strategies.

There are studies that yielded different results with regards to breast cancer patients and their spouse's adjustment to the illness. For instance, Northouse and Swain (1987) and Northouse (1989) did not find any difference of psychological distress between patients and their spouses. Baider and Kaplan De-Nour (1996) in their studies found the spouses had higher psychological distress than the patients. In contrast, Hoskins (1995) study showed patients having more distress than their spouses'. These studies may vary in their findings nonetheless they all show that psychological distress affects the patients and their spouses. As stated by Ben-Zur, Gilbar and Lev (2001: 33) the adjustment to the illness is inclusive of various components consisting of "*cognitive, emotional and behavioural responses to the diagnosis by the patients and their significant others*".

Research has shown that for women with advanced breast cancer, emotional support provided by the family assisted in the women having a positive outlook towards life (Bloom and Spiegel, 1984). The environment created by the family should be characterized by open communication and expression rather than constant conflict as this has an effect on the patient's adjustment (Spiegel, Bloom & Gottheil 1983). Manne (1999) maintains that spouses are the main providers of support in marriages and thus the responses of the spouses are crucial to the coping process (Manne *et al*, 2004: 660). Manne (1999) affirms women who reported receiving higher levels of critical or avoidant responses from their spouses had higher psychological distress. The spouse is expected to provide support, usually tangible emotional and financial, while adjusting to the new role that they have to assume in the household. Gottlieb and Bergen (2010: 512) stipulate "*that the closer the relationship, the greater the correlation among the several types of support, reflecting sentiment override, people we feel close to are perceived to be repositories of all types of support*". Furthermore, the spouse has to manage the possible psychological distress he or she may be facing. Studies have presented that if the spouses' distress levels are high and the responses conveyed to the patient are not efficient; the capacity to provide support to the patient is diminished (Ben-Zur, Gilbar & Lev, 2001).

Ell (1996; 174) is cautious about the simplicity implied in *“the assumption that patient recovery and adaptation will be negatively affected when family social ‘support’ is perceived as inadequate, misinformed, misguided, excessive or unwanted”*. The caution comes as a result of recognizing family members as subjects not objects, who have an unlimited amount of resources that the patient may draw from when they are in need of some type of support. The family system as a whole, experience the stress of the illness and engage in interdependent coping among members (Ell, 1996:174). Gottlieb and Bergen (2010:512) have a similar notion as Ell (1996), as they see social support as a *“mutual expression of affection that marks the relationship of the two parties”* and not a product which is brought by the provider to the receiver. Social support is subject to various factors; personal, environmental and cultural, one cannot assume that it is available in all social networks. In addition, one cannot assume it will be adequately provided in quantity and quality when people feel they need it (Gottlieb and Bergen, 2010:511). Ell (1996:174) argues that for optimal support to take place, clear communication from the patient concerning their need is required, and the provider of support has to make it known if they will be able to satisfy the need. The clear communication will decrease the possibility of miscommunication and misunderstanding and will also allow for both parties to be aware of the patients’ expectations.

Manne *et al* (2007: 380) contend that patients and/or their partners at times use protective buffering; it consists of *“hiding worries, denying concerns and yielding to one’s partner in an effort to avoid disagreement and reduce one’s partner’s upset and burden”*. The benefits of open communication may seem obvious however persons diagnosed with cancer have reported difficulties in communicating their feelings and have expressed a desire to have more talks about their fears and worries concerning the cancer.

Spouses have also reported reserving their innermost concerns, fears and thoughts, as they do not want to upset or burden their ill partner. Engaging in protective buffering can have negative psychological consequences as this interferes with the cognitive and emotional processing of the cancer experience. When a woman chooses to not disclose her concerns and worries to their partner, the partner does not have an opportunity to respond and provide the support the patient needs. The partner is

unable to fulfill his expected role as a support provider and confidante and this has the potential to increase distress for both partner and potential support receiver (Manne et al, 2007). Intimacy is also compromised during protective buffering as the partner does not have the opportunity to respond to the patient's needs and thus intimacy cannot be built or maintained.

Spouses are faced with a challenge when providing support; that may be beyond their control as the patients are the interpreters of the support. In other words, the woman could possibly misinterpret the intention(s) of the spouse. For example, a spouse may restrict their partner to partake in any household chores and this may be interpreted as the spouse being overprotective. However, a few months later, the woman may see the same behaviour from the spouse as appropriate and adequate. Another example is from Lethborg, Kissane and Burns (2003: 75) study of a spouse who was advised by the patient's doctor that the "patient had to live in as normal situation as possible. The spouse goes onto explain: "...So every time she sort of did a 'why me?' and 'I can't do anything today', I yelled and screamed and made her eat and made her drink and made her... you know I do the dishes anyway, but made her do what she normally did so that she wouldn't get into a 'why me?'..." (Lethborg, Kissane and Burns, 2003: 75).

In the beginning this caused conflict in their relationship however the spouse maintained that he was just following orders from the doctors. In this case the spouse was unaware and misinformed on how best to assist his wife.

Cutrona and Suhr (1994), Gottman (1979) and various others suggest; "*effective and supportive responses are characterized by expressions of acceptance, nurturance, validation and/or empathy*" (Manne et al, 2004: 661). Women who have been diagnosed with cancer are said to prefer emotional support from their family members rather than informational (Ell, 1996:174). The women do not respond well to the informational support especially when the spouse is not an expert in the field (Manne et al, 2004: 661). Women see criticism from spouses, spouses withdrawing during self-disclosure and receiving less support from their spouses than expected as unsupportive behaviours.

Hoskins (1997:105) presumes an illness such as breast cancer produces stressful events that couples functioning in *“traditional roles have to learn to deal with, these can accentuate the dynamics of ordinary interaction and intensify problems that already exist”*. Effective emotional support and communication within the couple is important for positive adaptation to the illness. Some of the ineffective adaptive behaviours mentioned by Hoskins (1997:105) include high negative emotions that are disproportionate to the conditions of the illness and decrease well being.

Informal carers report having to do ‘emotion work, defined by Thomas, Morris and Harman (2002:537) as *“the emotional effort made by individuals to manage their own feelings and those of others”*. Emotion work has now been accepted by some medical sociologists, they posit that it *provides “the ‘missing link’ between ‘personal troubles’ and broader public issues of social structure, itself the defining hallmark of the ‘sociological imagination’* (Mills, 1959, Williams and Bendelow, 1998: xiii cited in Thomas, Morris & Harman, 2002: 537).

Emotion work roles may have to shift during the cancer journey. This work that is typically carried out by women, as they are socialized to be nurturing and self-denying, may decrease and there can be an increase in self-absorption. The husbands who take on this unfamiliar territory can find themselves confused and in conflict as O’Mahoney and Carroll (1997) claim that, *“some have been socialized to be stoic during times of stress and to assume the role of protector”*. Thomas, Morris and Harman (2002: 538) indicate a carers’ responsibility for emotion work is considered to contribute to positivity for the cancer patient, *“manage feelings in order to sustain a sense of control over events”*.

The majority of carers and patients reported positive emotion work although one could identify some tension in some responses. One carer, who was the husband of a woman that had had her first treatment for breast cancer, explained how he would divert attention to his wife when people made statements such as *“it must be hard for you”*. He felt that he had to remain strong for the children as well, although when he was alone, he would cry (Thomas, Morris & Harman, 2002). One can see that

although the notion of being ‘positive’ and ‘strong’ is deemed as important amongst carers it can be difficult to maintain when they are alone. In partaking in the emotional work, Thomas *et al* (2002: 542) state spousal carers “*often symbolically shared in the illness and presented the struggle with the cancer as a joint one*”.

The dynamics of the family system are said to play a role in how effectively families adapt to the illness. Theorists have put forth that “*stability and strength of the family system depend on flexibility and during the course of treatment for breast cancer.*” (Hoskins, 1997:105; Minuchin, 1974; Baider and Kaplan-DeNour, 1988; Friedman *et al*, 1988 & Northouse & Swain, 1981). Therefore, it is desirable for a couple to be flexible for positive adjustment to occur however couples may have difficulties in redefining expectations of each other, especially if this did not occur prior to the cancer (Hoskins, 1997: 109-110).

Intimacy plays a significant role in support provision, particularly emotional support provision. Scholars such as Maslow (1968) and Prager (1995) consider intimacy as a prime psychological need and is an important contributor to individual well being (Manne *et al*, 2004: 589). Intimacy is composed of three parts “self- disclosure, attentive listening and understanding by one or both partners and positive affect between the partners” (Manne *et al*, 2004:589). Reis and Shaver (1988) defined intimacy as a “*process in which one person expresses important self-relevant feelings and information to another and as a result of the others response, comes to feel understood, validated and cared for*” (Reis and Patrick, 1996 in Manne *et al*, 2004:590).

Interaction is the base for intimacy the interactions consist of self-disclosure, which is the communication of personally relevant and revealing information to another person. It can contain facts, thoughts or feelings as well as non-verbal behavioural communication. Partner responsiveness is the second component and involves being the listener, the listener responds to the speaker by disclosing personally relevant facts, thoughts and feelings (Manne *et al*, 2004: 589). The speaker has to interpret the listeners’ statements as responsive for an intimate interaction to occur. Additionally, Pasipanodya *et al* (2012: 662) contend the spouse may “*behave or respond in a*

manner that was intended to communicate openness and interest but the patient might not interpret it that way”, this can have a negative impact on communication and constrain disclosure.

Manne *et al* (2004) results show *“perceived partner responsiveness mediated the association between self-disclosure and perceived intimacy and between perceived partner disclosure and intimacy”*. The partner’s self-disclosure affected the breast cancers patients’ feelings of intimacy directly and indirectly. The patient did not regard their self-disclosures as playing a significant role in their perception of closeness during their exchanges with their spouses. The authors put forth two potential explanations for their findings; the first is gender differences in the process of intimacy. The men and women reported feeling close and/or connected to each other during discussions when they felt they were cared for and understood by their partner. The difference came with regards to the role of self and perceived partner disclosure (Manne *et al*, 2004). The women felt intimacy with their partners when the partners disclosed and she perceived the responses to be caring, accepting and understanding. Whereas the males felt closer to the patients when both disclosed and the patient responds in an understanding and caring fashion. The second factor is the situational context; Manne *et al* (2004) assume *“the process of intimacy as well as the importance of how the healthy partner responds and handles issues may have been influenced by the cancer diagnosis”*.

As breast cancer has been termed the “we-disease”, the cancer experience can aid in the growth of the couple’s relationship in areas such as intimacy and communication. However, there are other couples that find the cancer experience brings difficulty in their relationships. Manne and Badr (2008) are of the opinion that intimacy is “an important and uniquely dyadic process that promotes a couple’s psychological adaptation to cancer and other health adversities (cited in Belcher, Laurenceau, Graber, Cohen, Dasch & Siegel, 2011). In a study conducted by Belcher *et al* (2011:666), they *“examined within-couple daily support processes and their association with daily relationship well-being in couples coping with early stage breast cancer”*. The *“everyday support processes”* consist of support receipt and support provision. Support receipt consists of *“the report of receiving or using support from a significant other”* and provision entails *“the report of providing*

support to a significant other” (Belcher *et al*, 2011: 666). Belcher *et al* (2011) believed receiving both records of support receipt and provision from both partners allows one to see the “*possible costs and benefits within a relationship*”. Belcher *et al* (2011: 666) place that receiving these perspectives also allows for “*the possibility that effects of support receipt from the perspective of the recipient are separate from the effects of support provision from the perspective of the partner*”.

Belcher *et al* (2011:670) found that “*support receipt and support provision were both unique and positive within-person predictors of daily intimacy*”. The provision of support from spouses resulted in greater intimacy for the couples “*regardless of whether patients reported support receipt*” (Belcher *et al*, 2011:670). The authors also found that support receipt and support provision not only benefited the patient but the spouse as well. The collection of dyadic data which was both partner and patient reporting on support provision and receipt, assisted in allowing Belcher *et al* (2011: 670) to see that patients were found to “*affect their spouse’s feelings of relationship intimacy by providing support, regardless of whether spouses report having been recipients of support*”. Women, who are diagnosed with breast cancer, are patients but they are also spouses who according to Kayser *et al* (1999) “*can be motivated to continue their role as supportive partners in the midst of recovering from illness*” (cited in Belcher *et al*, 2011: 670).

As mentioned, social support can have a favourable impact on breast cancer patients’ adjustment however the reaction to the disease can interfere with the provision of support (Dunkel-Schetter, 1984: 81).

Dunkel-Schetter (1984) looked at the following questions:

- What do cancer patients identify as supportive and unsupportive behaviours from others?
- Do cancer patients receive adequate support from others?
- Is the support received associated with adjustment? And in what ways?

The 79 participants of this study had breast or colo-rectal cancer, $\frac{3}{4}$ were breast cancer patients and $\frac{1}{4}$ were colo-rectal cancer patients. There were social support

measures that were selected *“to assess aspects of the respondents social networks, their perceived support from spouses or significant other and from the patient’s network as a whole, satisfaction with support, supportive and unsupportive behaviours and problems in interpersonal relationships”* (Dunkel-Schetter, 1984: 83).

The results presented participants identified their most helpful sources were family members, mainly spouses, children and siblings. The second most helpful sources were medical staff (physicians and nurses) and the third were friends (Dunkel-Schetter, 1984). The types of support identified were emotional, instrumental and informational. Emotional support was identified by terms such as love or concern, understanding, reassurance, encouragement. Presence companionship, increased attentiveness, willingness to let the patient speak, listening and direct expressions of love and concern were also identified as emotional support. Instrumental support was aid or assistance provided and informational support involved advice and information of a problem-solving nature (Dunkel-Schetter, 1984).

When type of support and who provided were examined simultaneously results showed emotional and tangible support being equally helpful when provided by family, friends and medical personnel (Dunkel-Schetter, 1984:84). The majority of the participants felt they received an adequate amount of support that consisted of love, assistance, information, advice/approval and understanding from their spouse and closest significant other (Dunkel-Schetter, 1984).

An interesting finding in a study conducted by Pistrang and Barker (1995) was that *“while women were willing to talk about the problems, they were loath to commit themselves, in numbers, to negative evaluations of their partner.”* An example given was of one woman who had rated her partner as *“moderately helpful”* said *talking was helpful because it got the feelings out, but he didn’t really listen, he forgot about it. His attitude is ‘get on with your life’. He’s not good with words; he finds it difficult to express his feelings. He sits and listens but I don’t know how much he takes in”* (Pistrang and Barker, 1995: 794). Although the woman rated her husband as ‘moderately helpful’ she expressed sentiments of not knowing how much he takes in.

One could argue that intimacy during the support provided by the spouse was lost, as mentioned earlier, the listener has to respond to the self-discloser in a manner that she finds satisfying so that one may say intimacy has been achieved. This also reinforces the notion of support being interpreted as helpful by the woman if it matches the situation being addressed. Therefore, the patient may have been looking for more nurturance, empathy and emotional support rather than dismissive advice giving (Manne *et al*, 2004: 661). When a woman expects their spouse to provide more emotion and nurturance support and less problem solving; their “*expectations may be violated when the spouse does not respond in the expected manner*” (Manne *et al*, 2004: 661).

In contrast, Hilton, Crawford and Tarko (2000) looked at men’s perspectives on individual and family coping with their wives’ breast cancer and chemotherapy. The article sheds light on the possible gender differences that occur when spouses are faced with their wives’ cancer. Men experience a wide range of emotions when their wives are diagnosed with breast cancer. This range consists of shock, disbelief, denial, anger, guilt, depression, anxiety, uncertainty, helplessness, fear, loss of control and isolation (Hilton, Crawford & Tarko, 2000). The concern is heightened during diagnosis, surgery and treatment although anxiety and stress can persist after surgery (Hilton, Crawford & Tarko, 2000). Hilton, Crawford and Tarko (2000) report other contributors to husband’s distress were a decline in marital satisfaction, lower family functioning, greater hopefulness and an increase of spousal demands. Men were also distressed and concerned about their ability to cope and feelings of exhaustion. The role changes that occur in the household, the management of these changes and disruption of daily life are significant concerns for husbands. During the cancer journey, Hilton, Crawford and Tarko (2000:440) reported men being “*challenged to carry out their usual roles, assume domestic roles, manage household tasks, provide physical care and emotional support and the marital and sexual relationship*”.

Kayser, Watson and Andrade (2007:404) believe that in order to fully understand “*the relationship between stress and health or mental health, one needs to examine coping as it occurs within the context of significant relationships*”. In this paper, the authors show how women (diagnosed with breast cancer) and their partners cope together with the cancer diagnosis and treatment (Kayser *et al*, 2007: 404). The dyadic coping

framework; views coping as being a process consisting of how “*couples appraise the illness-related stress, react to each other’s responses, use behavioural and cognitive strategies to manage stress and make meaning of the illness*” (Kayser et al, 2007: 405). Under the assumption that both parties are willing to further invest in their relationship given the stressor (cancer), if this is so, individuals are expected to be motivated to assist each other during hard times (Kayser et al, 2007: 406).

In this highly cited study, the authors conducted interviews with couples participating in a clinical research study called the Partners in Coping Program (PICP). The participants had to have: “*a diagnosis of nonmetastatic breast cancer within the last 3 months, currently receiving treatment, married or in a intimate relationship, both partners had to agree to be participants in the study*” (Kayser et al, 2007: 407-408). Kayser et al (2007: 409) found that couples “*appraised the stressor as a dyadic stressor, responding to the stress and validating each other’s response, coordinating their coping strategies and finding benefits of growth from the experience*”. The authors illustrated this process as a wheel as couples may regress to the previous stage during the process and may go through the cycle numerous times.

The relational qualities that were found in some of the couples were:

- “*Relationship awareness-thinking about one’s relationship in the context of the illness, thinking about the impact of the disease on the partner and the relationship and how to sustain one’s relationship given the extra demands of the illness*”. (Kayser et al, 2007: 410).
- “*Authenticity- Disclosing of genuine feelings to your partner*” (Kayser et al, 2007: 410).
- “*Mutuality- empathic responding, a way of relating in which each of the partners is participating as fully as possible in a shared experience*” (Kayser et al, 2007: 410).

The use of language was monitored in this study, such as identifying the stressor (breast cancer) as being the patient’s problem only, in such cases the “I” or “she” would be used by the partner, “we” was used if the cancer was acknowledged as affecting both partners.

The couples interviewed did not necessarily see the same changes as stressors; there was a patient who identified a change that has occurred due to her diagnosis as being their sex life. The patient's partner was not aware of this and felt he did not want to hurt her and thought about this constantly which made him more cautious, however he did not feel like there was a significant change in their sexual intimacy. Kayser *et al* (2007: 411) felt that the most important characteristic in this particular situation is the partners accepting the differences in their perspectives. There were couples that used emotion-focused and problem-focused types of coping strategies, there were others who used disengaged avoidance. Disengaged avoidance occurred when the couple's believe breast cancer to be the patient's problem and therefore the stressor was an individual problem. Others in this category stated that they had more pressing stressors than breast cancer. There was rare (if any) emotion talking by these couples; they did not find any positive benefits for themselves and/or their relationship because of breast cancer. The consequences of such a coping strategy may "*lower relationship satisfaction and mental health*" and couples may adopt unsupportive behaviours, causing mental distress for both individuals (Kayser, 2007: 415). When the spouse/partner is involved in the breast cancer, Northouse (1993:70) argues that it "*redefines breast cancer as a biopsychosocial problem that occurs in the context of an intense interpersonal relationship that affects, and is affected by, the disease process in reciprocal circularity*".

Manne *et al* (2006) also "*examined the association between three types of communication strategies couples may use to handle stressors they experience during and after breast cancer treatment and psychological distress and relationship satisfaction of women with early stage breast cancer and their partners*". There were 147 patients and 127 partners that participated in the study. The results showed that patient and partner's distress and relationship satisfaction was associated with how they perceived their communication about cancer related issues (Manne *et al*, 2006: 243). In other words, if both patient and partner participated in constructive communication, both their distress levels decreased and reported a higher relationship satisfaction (Manne *et al*, 2006: 243). The patients and partners that used 'demand-withdraw communication', which is "*a pattern where one partner pressures the other partner to talk about a cancer-related issue while the other partner withdraws*"

(Manne et al, 2006: 243), this was found to impact negatively on the levels of distress and relationship satisfaction.

Ultimately, the patient will perceive the support provided by the spouse as beneficial when it matches the stressful situation (Cutrona, 1990, Cutrona and Russell, 1990). Therefore, going back to ‘communication’ that was touched on earlier, clear communication is vital for “*providing support and it has been shown to influence both the patient and the family’s adaptation to illness*” (Ell, 1996: 174). It is crucial to note that help seeking and support provision will differ in relationships that are characterised by “*sociocultural variation and diverse structures*” (Ell, 1996:177).

2.6. Theoretical Framework

In this section of the chapter, the theoretical framework of the study is discussed. Very clear from the research question is the focus: the relational. Evidently, the relational is intrinsically bound with communication. Communicating with relational others, such as spouses and family members, could be complex and confusing. It is thus appropriate to utilize relational communication theory to help clarify these complexities. Littlejohn and Foss (2010:6) indicate that, “*sociologists focus on society and social processes and thus see communication as one of many social factors important in society*”. Step, Rose, Albert, Cheruvu and Siminoff (2005:3) assert that, “*communication theorists have long held that talk is the substance of relationships*”. Besides, this theory allows a better understanding of the research concerns. It will help to organize and explain how those diagnosed with breast cancer receive and interpret the support given by their family members. What, therefore is relational communication theory and how will this serve the research purpose?

The explanation of social behaviour is not straightforward and as such there are theories of relational communication. These theories developed from attempts to answer questions about interactions with others. Baxter and Braithwaite (2008) discussed these theories by separating them into those concerned with individuals, which they refer to as individual-centered theories; discourse/interaction-centered theories; relationship-centered theories. The relationship-centered theories are our

concern and the theoretical framework of the study. The specific theoretical framework for this study derives from the body of research that underpins the relationship-centered theories. These research works are contained in the *Pragmatics of Human Communication*. The main thrust is “*pragmatic (behavioural) effects of communication*” and properties or “*axioms*” of human interaction. The proposed axioms include: “*...all behaviour in an interactional situation has message value (communication)*” (Watzlawick, Beavin & Jackson, 1967). This comes after the premise that it is impossible for one not to communicate. Thus “*activity or inactivity, words or silence all have a message value: they influence others and these others, in turn, cannot not respond to these communications and are thus themselves communicating*” (Watzlawick, Beavin & Jackson, 1967: 49).

Watzlawick, Beavin and Jackson (1967) state further that communication does not only take place when there is intent, when one is conscious of it or when there is understanding. A study conducted by Kagawa-Singer and Wellisch (2003) examined the perceptions of women concerning their spouses’ support during their breast cancer journey. The participants included 13 Euro-American (EA), 18 Chinese-American (CA) and 15 Japanese-American women (JA). Kagawa-Singer (2003:30) had three themes that emerged from the interviews: vulnerability, nature of the marital relationship and sources of dissonance. In the branch of vulnerability, all the women expressed a need to be dependent on their spouses however the amount of dependency the women felt they could exhibit varied for the ethnic groups. Kagawa-Singer and Wellisch (2003:31) report that all the women expressed a need for emotional dependency and were frustrated that “*their husbands did not seem to appreciate their vulnerability and need for dependency*”. Culture also had an influence on whether women could express their emotional dependency. The EA women could be dependent however the CA and JA women felt they could not (Kagawa-Singer and Wellisch, 2003: 32). Kagawa-Singer and Wellisch (2003:32), assert that the traditional Japanese culture “*teaches women to sacrifice their emotional and physical needs for the family and not to assert their identity, even in times of need*”. The above was manifested in husbands not attending to their wives in the form of comfort and emotional support; they saw their wives as comforted, supporter and ‘role filler’ this was communicated by the JA women. The CA women received tangible support however reported that their husbands did not provide emotional support. The CA

women received both emotional and tangible support, however, were still expected to maintain their nurturer role (Kagawa-Singer and Wellisch, 2003: 32).

Kagawa-Singer and Wellisch (2003:33) found differences between the groups on *“their expectations in the basic objective of the marriage relationship and the means to achieve this objective”*. There were women who practiced harmony in their relationships and others who chose intimacy. Kagawa-Singer and Wellisch (2003) assert that the two are mutually exclusive. They are defined by the scholars as: *“intimacy requires that the individuals involved interact to find areas upon which to disagree in order to identify their individuality and mutual relationship...This usually requires dialogue between the partners”* (Kagawa-Singer and Wellisch, 2003: 33). Harmony differs in that Kagawa and Wellisch (2003:33) argue that it *“requires avoidance of conflict or disagreement and respect for the other by not finding differences...The objective is to know what the inner being of the other is, but without having to ask”*. This results in partners not asking or telling the other about their private feelings. An example was a CA respondent did not share her feelings with her spouse because she did not want to worry him after he came home from work tired. In summation, the CA and JA women practiced harmony and the EA women were firm on intimacy. In relating the above to the framework, one has to be mindful of cultural differences (if any) when analysing participants' responses.

The other proposed “axiom” is: *“every communication has a content and a relationship aspect such that the latter classifies the former and is therefore a metacommunication”*. The point is that every communication has dual dimensions: content/report and relationship/command. Watzlawick, Beavin and Jackson (1967:56) explains that the report aspect of the dualism conveys *“information and is, therefore synonymous in human communication with the content of the message”*. Watzlawick, Beavin and Jackson (1967:52) illustrate that the report aspect of the dualism conveys *“information and is therefore synonymous in human communication with the content of the message”*. He adds that the: *“The command aspect, on the other hand, refers to what sort of a message it is to be taken as, and, therefore, ultimately to the relationship between the communicants.”* (Watzlawick, Beavin & Jackson, 1967:52). Content is said to *“refer to the object or referent specified in the message, whereas relational characteristics refer to the reciprocal rules of interdependence that*

combine the persons into an interactive system” (Millar and Rogers, 1976:87). For this study, what is crucial is that this model allows an understanding of the effect of communication on the receiver and at the same time the receiver’s reaction. Thus family support, which is the study’s concern, is focused upon as what is invariably sender-receiver relation as mediated by communication.

The interactivity of the communication process becomes vital in *measuring* family support as distinct from the one-way model of the speaker to the receiver. “Through the process of message exchange, system members reciprocally define self in relation to others and simultaneously, define the interactive nature of their relationship. Rogers and Escudero (2014:37) highlight that *“communication is seen as the life-giving, social-sustaining essence of relationships, the interactive process by which relationships come into being, take shape, are built up or torn down in the ongoing ebb and flow of their evolutionary course”*.

It is useful to point out that Watzlawick, Beavin and Jackson (1967) suggests that there are digital and analogical aspects in human communication. Watzlawick, Beavin and Jackson (1967:62) define analogic communication as *“all nonverbal communication”*; this includes body movements and *“posture, gesture, facial expression, voice inflection, the sequence, rhythm and cadence of the words themselves and any other nonverbal manifestation”*. The digital communication refers to the verbal language used. As previously mentioned, *“every communication has a content and a relationship aspect, therefore we can expect to find that the two modes of communication not only exist side by side but complement each other in every message. We can further expect to find that the content aspect is likely to be conveyed digitally whereas the relationship aspect will be predominately analogic in nature”* (Watzlawick, Beavin & Jackson, 1967:64). This strengthens the theory and in interviewing the participant in this study, a rounded picture of the support can be captured with focus on both dimensions. This means that one gains more from the theory than what its critics would say. The advantage is that the communication process in support giving and support-receiving is viewed dynamically and interactive than static and linear.

Earlier on in this chapter, which reviews the literature, it was mentioned that a diagnosis of breast cancer could interrupt the dynamics in a family. The family can be seen as system thus fitting the definition of “*stable with respect to a certain of its variables if these variables tend to remain within defined limits*” (Watzlawick, Beavin & Jackson 1967: 134). Watzlawick, Beavin and Jackson (1967) expand on this by explaining that: “*the behaviour of every individual within the family is related to and dependent upon the behaviour of all the others*. Thus in the case of a diagnosis of breast cancer the psychological, physical and social well-being of the woman can be affected and in turn these changes will usually have an effect on other family members, especially in terms of their own psychological, social or even physical health.

The changes that occur for the patient can be brought upon by thoughts about their existentialism. As the patient has been living, they have been, according to Watzlawick, Beavin and Jackson (1967), gaining information about the world around them and one of the ways this knowledge is gained is through communication and consequently one cannot separate the concepts of existence and communication. The environment (the world) has an impact on the patient and it “*comprises a set of instructions whose meaning is by no means self-evident but rather is left up to the [patient] to [decipher] as best as [she] can*” (Watzlawick, Beavin & Jackson, 1967:258). So, the environment has an impact on the individual and accordingly the individual’s reactions have an impact on the environment; these interactions are seen as non-random and governed by ‘meaning’. On that account, Watzlawick, Beavin and Jackson (1967) posit that, existence is a result of the relationship between the individual and the environment.

This chapter has reviewed some of the available literature regarding the history of breast cancer, the global and local statistics, and social support for women diagnosed with breast cancer. Although the South African literature on breast cancer was explored, it is limited. Despite this, the review served to provide an overview of the key issues surrounding breast cancer. Finally, the theoretical framework underpinning this study was outlined. The following chapter describes the research process.

Chapter Three: Methodology and Methods

3.1 Methodology

The study is qualitative and used the phenomenological approach. As suggested in the introduction, the literature reveals a gap in microsociological studies of social support to women diagnosed with early stage breast cancer in South Africa. Thus, opportunity for such a study presents itself. In addition, such a study would enable the discovery of the essential elements of the lived experiences of women diagnosed with breast cancer. Therefore the phenomenological approach, which is informed by the phenomenological philosophy, is essential. One is aware of the various interpretations of phenomenology and thus has chose to adopt Giorgi's interpretation, this being the Descriptive phenomenological approach. Utilizing this methodological approach enables a connection between consciousness, experience, presence, meaning, intuition, and intentionality (Giorgi, 1997). Giorgi (1997: 236) posits that the 'phenomena' in phenomenology means "*the presence of any given precisely as it is given or experienced*". He elaborates "*phenomenology begins its analysis of intuitions or presences not in their objective sense, but precisely in terms of the full range of "givenness", no matter how partial or marginal, that are present and in terms of the meaning that the phenomena have for the experiencing subjects*" (Giorgi, 1997: 236).

Giorgi and Giorgi (2003) indicate that the phenomenological methodology illuminates lived experiences exactly as perceived, described and felt by participants with an awareness of the relational subjectivity of "*embodied self-world others*". They added that it is an empirical research method which aspires to systematically, methodically and critically examine the lived experiences of others, noting that the methodology delves into experiences using the in-depth interview technique to elucidate the meaning of experiences in ways that can be better appreciated than use of the quantification method.

The dynamic nature of the relational communication theoretical capturing of the focus of the study awakens one to alter the description of the participants without imposing meaning of what is described in pre-defined categories. To expand on the previous point; it is important to grasp the whole meaning of the lived experience of the

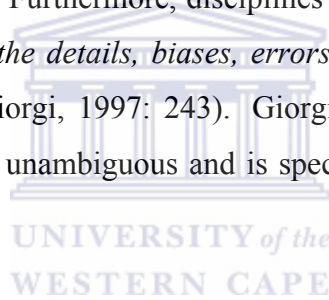
subject, *“instead of dividing it into parts without understanding the basic meaning structure, which gives sense to the whole experience”* (De Castro, 2003:47). If the prior is not taken into consideration, one faces the risk of talking about abstract concepts that do not represent or reflect the subjects lived experience (De Castro, 2003:48). Giorgi and Giorgi (2003) encourage researchers to “bracket” their own assumptions pertaining to the phenomenon in question by refraining from having a static sense of objective reality of oneself and the participants.

Methodologically; as put forth by Giorgi, the descriptive phenomenological method which has both descriptive and interpretive moments, require that a researcher remains careful to attend to each type of act in unique ways. So, in this study, how did this happen? What was required of me was to immerse myself with the subjects and their descriptions so as to get a sense of the ways that they experience the support given by their family members as described by them, and be able to describe this as actual lived experiences. Thus it was crucial that I do not as Sokolowski (2000:25 cited in De Castro (2003:48) points out: *“turn the abstractum into concretum, as we would be talking about experiences and categories that do not exist in the person who lives that experience”*. In the process of doing this, it becomes important to avoid theoretical and speculative interpretation in order to flesh out the full lived meaning inherent to the descriptions themselves (Giorgi, 2009:127). In therefore analysing the data it becomes crucial to ensure what Giorgi suggests: *“the results reflect a careful description of precisely the features of the experienced phenomenon as they present themselves to the consciousness of the researcher”* (Giorgi, 2009:130-131).

How will this work for the study? Proponents of this methodology point out that it does not involve deduction nor induction in order to find meaning, rather the researcher has to intuit what is essential to the phenomenon being studied. Thus in the context of this study, intuition will be used in order to get a sense of the lived meaning of each description as to relate that to what is known about family social support. The (lived meaning) description is retrieved from the content of the communication.

As earlier mentioned, the whole process in this qualitative method is guided by the 'empirical phenomenological method'. Phenomenology seeks to "*understand what motivates a conscious creature to say that something is*" (Giorgi, 1997:237). The phenomenological method allows for the subject to give an account of the phenomena as it presents itself to his or her consciousness and what is given to the researcher by the subject is "*understood precisely as they are presented, without addition or deletion*" (Giorgi, 1997:237).

In the modified philosophical method for scientific purposes, the description is the first step. In this step, according to Giorgi (1997:243) the researcher collects descriptions "*from others from the perspective of the natural attitude*". Obtaining descriptions from others decreases the possibility of bias and natural attitude is preferred as during the reduction stage, the researcher seeks to understand natural attitude better (Giorgi, 1997). Furthermore, disciplines concerning human science are interested in understanding "*the details, biases, errors and prejudices that we carry with us in everyday life*" (Giorgi, 1997: 243). Giorgi (1997: 243) asserts that this entails that the description is unambiguous and is specific with "*few generalisations and abstractions*".



In the reduction stage, which is the second stage, the researcher has to put aside any knowledge he or she may have concerning the phenomena and has to be fully present in the phenomenon that is being described by the subject (Giorgi, 1997). The researcher has to take the phenomena described as not an objective description of the event but an "*indication of the event that the subject witnessed or was present in*" (Giorgi, 1997: 243). The above mentioned has to be done through the lens of the sociology discipline.

Once all the data is collected, the phenomenological method informs one to read through all of the data before the analysis begins. In this action, one is able to get a global sense of the data and not to thematize it based on previous awareness of the subject (Giorgi, 1997:245). One then formulates meaning units, using the subjects' everyday language, derived from rereading the data. This activity requires the

researcher to have an attitude that is conducive to the discovery orientation of this exercise (Giorgi, 1997).

(Giorgi (1997: 248), states that phenomenology is of the point of view that “ *the life-world is pre-theoretical and prescientific and not yet theoretical or scientific in itself*”. Therefore, “*expressions must be taken up, examined and re-described more rigorously from the perspective of a chosen discipline*” (Giorgi, 1997: 248). In other words, one has to take the information gathered and transform it into language that is in accordance with the field of sociology.

3.2 Research Design

The study is a basic qualitative study and the underlying philosophy is phenomenological perspective. An important highlight is that a general phenomenological perspective was used to illuminate “*the importance of using methods that capture people’s experience of the world*” (Patton, 2002:107).

Research is ultimately “*inquiring into or investigating something in a systematic manner*” (Merriam, 2009:3). In the case of basic research a researcher uses this method when motivated by an interest in knowing more about a phenomena and extending the knowledge.

Partaking in qualitative research means an “*interest in understanding how people interpret their experiences, how they construct their worlds, and what meaning they attribute to their experiences*” (Merriam, 2009:5).

There are four characteristics that contribute to the nature of qualitative research. The first is: focus on meaning and understanding, individuals who partake in qualitative research are interested in how people interpret their experiences, they are concerned with learning about a phenomenon from the participant’s perspective and not theirs.

The second characteristic is the researcher is seen as the primary instrument, for the collection of data and analysis. The third, ‘an inductive process’, qualitative research

is usually inductive, meaning researchers “gather data to build concepts, hypotheses, or theories rather than deductively testing” (Merriam, 2009:15).

The last characteristic is rich description; qualitative research is seen as full of descriptions of the context, the participants involved and the activities of interest (Merriam, 2009:16). One of the primary purposes for qualitative researchers is “to provide a framework within which people can respond in a way that represents accurately and thoroughly their points of view about the world, or that part of the world about which they are talking” (Patton, 2002:21).

After gaining more knowledge on qualitative research I saw it appropriate to utilize it for this particular study, as I was fundamentally interested in my participant’s stories about their social support systems.

3.3 Sample Selection

The sampling method used for this study was the snowball method, it involves locating participants who are part of the target population and asking the said participants to assist in providing information needed to locate other members of that population (Babbie, 2001:191). This approach is useful for locating individuals who will be key informants for the study or individuals who are not easily accessible or easy to locate. From prior experience with my honours thesis, I was aware of the difficulty one can face when trying to locate women who have been diagnosed with early stage breast cancer. Thus, for this study in my first attempt of locating participants, I went to the Cancer Association of South Africa (CANSA) office in Mowbray to see whether they could be of any assistance in locating participants. I was informed that they could not assist however referred to the breast clinic at Groote Schuur. Upon arriving at Groote Schuur, I was informed to contact the Head of the Oncology Department, after a string of email correspondence I was informed that I would have to submit my proposal and accompanying forms to the University of Cape Town ethics committee and wait for their approval. He also cautioned that he could not guarantee how long the process would take and an alternative was to contact Tygerberg Hospital and ask their breast department for assistance. However, this

proved unnecessary and the head of the breast department at Groote Schuur was contacted and permission to conduct interviews with the women attending the breast/mamma clinic was obtained. At the clinic the head nurse assisted by briefly informing the women about my presence and referred those that were willing to participate in the study.

The desired sample size was fifteen women however only ten were interviewed; this was due to some being called for their chemotherapy and them experiencing excessive fatigue. One may question the sample size but there are no concrete rules for sample size in qualitative inquiry, Patton (2002: 244) puts forth that sample size is dependent on “*what you want to know, the purpose of the inquiry, what’s at stake, what will be useful, what will have credibility, what can be done with available time and resources*”. In general it could be argued that the number might not yield the type of result that will reflect the experience, this was mitigated by the extent of the in-depth interviews. Additionally, issues of validity may be raised because of sample size Patton (2002:245) posits that validity, meaningfulness and insights has less to do with sample size and is based more on the robust information and the observational and analytical capabilities of the researcher.

3.4. Methods

As mentioned, this is a qualitative study. In order to gather data, face-to-face interviews were conducted with participants. A semi-structured interview schedule (set of questions, see Appendix A for the questions) was used. Notes taken while observing support group meetings were also used and formed part of the findings.

3.4.1. Interviews

An interview is defined by DeMarrais (2004: 55) as a “*process in which a researcher and participant engage in a conversation focused on questions related to a research study*”. Thus the principal reason for engaging in discussion is the interviewer is seeking information about what the interviewee thinks about a certain topic. Patton (2002:340-341) explains: “*We interview people to find out from them those things we cannot directly observe.... We cannot observe feelings, thoughts and intentions. We*

cannot observe behaviour that took place at some previous point in time. We cannot observe situations that preclude the presence of an observer. We cannot observe how people have organized the world and the meanings they attach to what goes on in the world. We have to ask people questions about those things. The purpose of interviewing, then, is to allow us to enter into the other persons perspective.”

As I was interested in the experiences of social support for women diagnosed with early stage breast cancer, I opted to make use of the semi-structured qualitative method. The semi-structured sheet of questions was utilized to ensure that the crucial issues, such as availability and usefulness of support, were thoroughly discussed in the interviews. The structured elements of the questions only pertained to the demographic section of the questions. Giorgi (1997) advocates for questions that are open-ended and broad in order for the participants to extensively describe the phenomena. The purpose of providing a platform where the participant is able to be open and extensive allows for a description that will be sound and particular and “*as faithful as possible to what happened as experienced by the subject.*” (Giorgi, 1997: 245). I was aware of the potential pitfalls of having a semi-structured questionnaire however I took caution not to lead the participants in my questioning.

A challenge that I faced during the interviews was a restructuring and rewording of questions; which necessitated a change in the title and focus of the study. A decision had to be made then and there as my previous supervisor was unavailable for consultation and I had limited time in the field.

The duration of the interviews was 30-45 minutes; the interviews took place in a office space at the outpatient clinic located at Tygerberg hospital. I could not keep the participants for longer as they were either waiting to be called for consultation or for chemotherapy. Before the formal interview began, I started with a brief introduction, I then went through the informed consent form, which highlighted the following points: the purpose for the collection of the information, who the information is for and how it will be used, what will be asked in the interview and how the responses will be handled, issues of confidentiality and anonymity (Patton, 2002: 405). The interviews were tape-recorded. This proved to be effective as it can be become difficult to

capture everything in writing that the interviewee is saying without restricting the flow of the conversation. Additionally, I wanted the interviewee to feel that I was present and attentive to what she was communicating. One was cautious during the interview during the interview and between interviews that the recorder had not stopped or malfunctioned.

In addition to the interviews, my analysis will consist of data from a support group that I attended. Three women administer the group; two of which are breast cancer survivors. The group is open to men and women, who have cancer, have survived cancer and their carers. At the start of every meeting the women open with a prayer and introduce themselves, for the weeks I was there, I was introduced as well. The support group had an average of twenty (20) attendees per week and I found an average of three (3) women who were diagnosed with breast cancer that were in attendance. I attended the support group for two months and the information I received will be discussed in the analysis/discussion section of this paper. But, first the ethical concerns pertaining to research, need to be discussed.

3.4.2. Ethical consideration:

The Senate Research Committee of the University of the Western Cape granted ethical consent before the study could begin.

Ethics in qualitative research can be complex, there are ethics that scholars have agreed upon, disagreements on some and other situations that require the researcher to “think on their feet” because he or she is in the field and the situation has not been tackled in a textbook or academic paper. The ethics process begins at whether one’s topic of interest can be explored without harming the subject participants and/or the researcher, this decision is made by an ethics committee. Before the interviews began, I explained verbally what the interview was about and what it was for, I then went through the consent form, a copy is contained in the Appendix (See Appendix B). I allowed the participants to take a moment and review the consent form for themselves and sign where highlighted. I then noted that the topic is sensitive and if at any point they wanted to stop the interview, they had every right to do so.

The Belmont report (created by the National Commission for the Protection of Human Subjects of Behavioural Research); has three main principles for guiding researchers on ethical conduct,

- *“Respect of persons: participants welfare should always take precedence over the interests of science or society. Participants should be treated with courtesy and respect, and they should enter into research voluntarily and with adequate information.*
- *Beneficence: researchers should strive to maximize the benefits of the research for wider society, and to minimize potential risks to research participants.*
- *Justice: researchers should ensure that research procedures are administered in a fair, non-exploitative, and well considered manner.”* (Hennik, Hutter & Bailey, 2010: 63).

3.4.3 Data analysis

The data set consisted of transcribed interviews and field notes. The analysis of the data began after all the interviews were concluded and transcribing completed, the transcripts were then read over multiple times in order to familiarize and understand what was in the raw data. Bernard (2006) believes that the ocular scan method is the prime starting point when analysing data. It is a time when the researcher interacts with the raw data by simply reading the transcripts and getting an understanding of what is occurring in the text. Once the ocular scan process had been exhausted, one started to look for themes and patterns. The various themes were highlighted using different colours. Terre Blanche, Durrheim and Kelly (2006) advise using the same language that the participants used when forming categories. I had to be careful that they did not merely summarize the raw data; similarities, differences and interesting aspects had to be found and analysed on their own and also in relation to the literature.

This chapter has described the methods used and the research process. The findings are discussed in the next section.

Chapter Four: Findings/Results

The previous chapters introduced the topic and the research question, reviewed the literature and outlined the methods used to gather data. This chapter discusses the research findings and analyses the results derived from the face-to-face interviews, as well as the observations made during support group meetings.

The findings revealed were interesting and some elements could be related to the literature. As discussed in Chapter Three, I had to make adjustments to the study's aims and focus during the interviews. Consequently, I found that there were some disadvantages and I did not have enough time to review questions and expand based on the new aims and focus. Nonetheless, I was able to begin exploring women's experiences of social support and whom they receive it from. In the next section, I attempt to present the findings and have ensured that the women's 'voices' are communicated as authentically as possible, so as to engage the reader, as if they were present during the interviews or support group meetings. First, the demographic information obtained about the participants is examined.

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4.1 Demographic background/s

For the purposes of this study, ten (10) women with early stage breast cancer were interviewed. All of the women were diagnosed with breast cancer in 2015, and all were receiving their second round of chemotherapy on the day of the interviews. The youngest participant was thirty (30) years old and the oldest, seventy-six (76) years. Four of the participants were employed, the rest were on pension or received financial assistance from their families. All of the participants identified themselves as coloured¹. In addition, the experiences of two of the three women who run the breast

¹ The term coloured originates from the Apartheid era and the system of racial classification used

cancer support group were included in the study². Where relevant, the views expressed by attendees are discussed.

The demographics of the individuals who attended the support group while I was there were mainly coloured and black women from a low socio-economic background. Two of the three women that facilitate the support group are themselves breast cancer survivors. The two women who are cancer survivors gave me permission to include their cancer experience. In the interest of ensuring anonymity, one participant will be referred to as Mary and the other as Jane. They identified themselves as coloured and are widows. Both of these women lost their husbands due to cancer.

Apart from the biographical data obtained from participants, the interviews focused on their views and experiences. How they found out about their cancer, who they told, their sources and types of support, the emotional and unexpected aspects of the disease and the treatments they received are some of the key issues dealt with next.

4.2 Learning about the diagnosis

Receiving a diagnosis of cancer is challenging for anyone and people respond in different ways to the news. This is compounded by the difficulty associated with sharing the diagnosis with loved ones. Thus, before obtaining information about the participant's support system, I began with asking about their initial response to their diagnosis. All of the women expressed shock and disbelief upon receiving their diagnosis. Many questioned why it was happening to them. One participant said that she was overcome with anxiety and another expressed how fearful she was. A participant described her response:

“Oh... I was shocked. (Looks around the room), very shocked, I was emotional and it (takes a breath) was hard to believe. I [have] a lot of things in my mind”

² The support group is held every Tuesday. It is open to men and women who have cancer, have survived cancer and their carers. The organisers open with an introduction about themselves, an explanation about what the group is for, and a prayer.

(draws another deep breath), She continues, *“In the beginning it was fear and a lot of questions, why?”*

The initial response of shock seemed to be coupled with the question ‘why me?’ for the majority of the participants. The following is an answer from a sixty-eight (68) year old woman, who has a long-term partner.

“I asked myself, why me? I am a fun, active person, I do ballroom dancing, I am happy, I just did not understand why me?”

Another participant, who is sixty-four (64) and a widow, said she did not understand how she has cancer when no one in her family has ever had cancer. She asks, *“why me? At this age?”*

The participant’s responses were in line with those documented in many of the previous studies highlighted in the literature reviewed. The initial response of fear, shock and the questioning, that followed, was common among women in this predicament. Individuals faced with cancer diagnosis, at some stage, tend to question why it has happened to them. Lewis (1994) was a nurse in an oncology department and told her story of when she was diagnosed with breast cancer. Although she worked with cancer patients daily, she did not take the news of her diagnosis calmly.

The ‘why me?’ question was accompanied by other questions for some participants. However, the participants were reluctant to elaborate on what these questions were. When asked if these questions had been answered, some replied positively and confirmed that they had, others were still in search of answers but were optimistic they would find them. After receiving the positive diagnosis, the next challenge for the participants related to sharing the news with others.

4.3 The first person told

As a way of trying to establish an introduction to their support system, the women were asked whom they first told about their diagnosis. Their answers varied from mother; partner, brother, son, daughter and sister. The reasons given were these

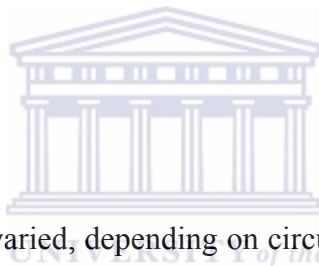
individuals usually accompanied them to their visits, or they deemed them as the closest person to them. One participant informed her brother first; when asked what his response was she responded:

“He was a little bit quiet but I was crying (pause) and so he drove over to me and he let me cry (pause). It was the last time I cried, I never cried again. I only feel emotional, but I never cry.”

Another participant, the youngest in the sample, who is thirty (30) years old, told her mother, who is a cancer survivor. She explains her mothers’ response:

“Denial first, and then obviously acceptance from then on. Um ja, and she had cancer.”

4.4 Types of support



The sources of support were varied, depending on circumstance. The types of support the women received were practical, tangible, financial, emotional and spiritual. One woman, who lives on a farm with her twenty-one (21) year old son, explained how her son is proactive with the work around the house. She also has her sister and friends who assist her. The participant responded:

“There is lots of help from people in the farm, friends, there’s always someone. Except for times when I say I want to sleep or be alone”.

One fifty-eight (58) year old, who was employed part-time, was hesitant to go into detail during the interview. However, she conceded that she received tangible assistance from her daughter-in-law and her eldest granddaughter; this consisted of cleaning the house, cooking and accompanying her to the hospital on some days. The person she confides in emotionally is her manager at work. According to her, her manager has been very helpful in that aspect. The participant revealed how her son took her diagnosis “*very hard*”. This could possibly be a reason for her turning to her

female manager for emotional support. She did not want to elaborate on this further, so the discussion around this issue ended.

The sixty-eight (68) year old ballroom dancer is in a long-term relationship. She told her partner, who is eighty (80) years old, first about her diagnosis. Her partner always accompanies her to her appointments. The partner has been very supportive and assisted her in developing a positive outlook. According to her, he did not allow her to wallow in her negative thoughts and this has assisted her in returning to what she terms her “*old, cheerful self*”.

Similarly, Jane, a support group organizer, had what some would call an ideal experience excluding her husbands’ passing. When she was diagnosed with breast cancer, she describes her husband as being “extremely supportive.” He encouraged her to talk about her illness and be positive. Her husband was then diagnosed with cancer himself and continued his positive approach. He was active in support groups and also started a group for their residential community. Jane’s husband persuaded her continue with the support groups after his passing. Jane attributes her strength and willingness to fight her cancer to her husband and her faith; she carried her husband’s words and encouragement even on days she viewed as difficult.

A woman attending the support group meeting related a similar view and experience. She shared her testimony with the group. She was diagnosed with breast cancer at the age of thirty-one (31). Upon receiving the news, she was shocked and fearful. She felt she was too young. She struggled with her treatment, particularly chemotherapy, so she terminated her treatment early, against the advice of doctors, but ultimately had to return to it. During her radiation treatment, she fell pregnant with a girl, which had always been her dream. However, she had to terminate her pregnancy as she was still undergoing treatment. Through her cancer journey, her husband was her support provider. Despite suffering two heart attacks, he was able to take care of her and their responsibilities at home even at her worst. She constantly had to remind herself to stay strong for her children. This lady shared her story as encouragement for others to not give up, no matter the adversity they may face during their cancer journey.

In the above cases an optimistic partner who encourages their partner to share their enthusiasm, yielded positive results. This is not always the case. There are instances of women disagreeing with the partner's optimistic outlook, and/or interpreting it as a sign of disinterest in engaging in meaningful discussion about their emotions towards their illness. This was demonstrated in the literature. In this study by Lethborg, Kissane and Burns (2003:75) the husband of someone with breast cancer, revealed how a doctor had advised him to try keeping everything as normal as possible at home and not allowing his wife to have a negative outlook. But, unfortunately this did not have the desired effect and made his wife hostile towards him. Thus, partners have to take caution when broaching a subject such as breast cancer with the intention of bringing optimism to the situation.

Interactions with the support group organisers also showed how negative feelings towards the person with breast cancer could emerge. Mary, another one of the organisers, was diagnosed with breast cancer six (6) years ago. She had a mastectomy, followed by chemotherapy and radiation treatment. Mary's main support came from her children. She referred to her husband as a man "*who did not talk much*" and thus they never discussed her breast cancer. As she was progressing through her treatment, her husband was diagnosed with stomach and liver cancer. During this time, she had to stop being the patient and became the carer. She accompanied him to all of his hospital appointments, although he never allowed her to sit in during the doctor's consultations. In the last few weeks before her husband passed, Mary lived in the outside rooms of their home. This was a request from her children as her husband had become hostile towards her. Nevertheless, Mary sees herself as a "courageous" woman and finds her strength in her faith. She attributes her ability to cope with her cancer, her husbands' cancer and the lack of communication to the mental strength and faith that she maintains.

Although, the availability of support was important for all the support group attendees, there were a significant number that expressed a lack of support from their families and friends. The organisers, Mary and Jane explained that families are not equipped to manage individuals with cancer and therefore shun the patient away, moreover they argued that families may be afraid of interacting with someone who reminds them of death. Mary advised carers who attended the support group to hide

their fear from the patients and to exhibit strength even when it is difficult, her justification was this allowed carers to be physically and mentally available for the patient.

A common theme that emerged at these meetings was that patients felt that they had to be strong for their families. This meant putting their families and spouses before themselves. Women felt they had to “stay strong for children. Interviewees expressed similar feelings. Throughout fieldwork, hope was referred to often, even amongst the fear. The cancer was objectified thus made not to be an illness that defined them. Many of the women questioned their faith and religious beliefs, while others focused on spirituality and turned to religion for refuge.

4.5 Emotional aspects of breast cancer

As one would assume, and as has been shown in literature, a diagnosis of breast cancer can bring about emotional distress. Women may find themselves highly emotional and unable to pinpoint why or how to manage their emotions. This can pose a challenge for soliciting support as they may not be able to accurately communicate their feelings and the support providers may be unable to assist because of a lack of knowledge on how to approach the individuals seeking help.

One of the participants, who possibly were unaware of her emotional state, mentioned that the last time she had cried was on the day of her diagnosis. However, she cried throughout the interview. She began crying shortly after her response to the question of whether her brother had spoken to her about his feelings regarding her diagnosis. In her words:

“Um... no, I have thought about it, but I haven’t asked him. I sometimes think about what was or is he thinking. My baby brother cried a lot, he can’t believe it (Pause, fighting back tears). I tell him to stop crying because he makes me weak and I don’t want to be weak for the sake of my children.” (Participant began crying)

The participant was probably overcome with emotions because of the interview, nevertheless, it makes one wonder if she has not cried in between the time of her diagnosis and interview, and simply not processed that she was crying. This participant made a distinction between crying and being emotional. My lack of probing, due to the sensitive nature of the situation and topic, resulted in not receiving a possible explanation for the distinction.

On the other hand, the lady who lived on the farm was completely aware of her emotions. When asked how she has been emotionally, her response was:

“I won’t say I feel. (Pause). It’s just (pause), sometimes when something happens at home then you feel so emotional and just cry”.

The interviewee proceeded by explaining a plumbing incident that occurred in her home, it caused her to be preoccupied most of the day and left her emotional and crying. The incident required her to do some physical activity and use her arms. Since she had a mastectomy in her left breast, this has caused restricted movement in her left arm. When probed on what she was feeling at that moment and what caused her to cry, her response was: *“It was a feeling of hopelessness.”* (Pause).

The thirty (30) year old participant had spoken to her mother the night before the interview on how anxious she was for her second chemotherapy session. She speaks to her mother when she is having difficult times and according to her, *“sometimes you want to give up and stuff like that”*. The participant found it easier to speak to her mother as she felt her mother could relate since she is herself, a cancer survivor. This participant also spoke of how she had to stop relations with a man she had started getting to know. Her reasoning was:

“It (breast cancer) changes the dynamic totally because you don’t know if the person now is with you because they want to support you. I am not for a saviour complex, I don’t need to be saved, it is going to be strenuous because a lot of the times I am irritable or just don’t feel well and other times I need your support and other times I push you away. So, you question, why would someone put

themselves through that". She went on to suggest that she would begin dating again once "it's all over" (cancer treatment).

The lack of selfishness in this statement was fascinating; it also seemed as if the participant had come to a conclusion on her own about receiving support from possible partners. One could argue that this was also a defence mechanism for the participant, she did not want to second guess the reason a male was in her life.

The fifty-five (55) year old woman, whose main support system is her brother expressed what she would like from her family. Most of all, she did not want them to feel sorry for her. *"They must be normal with me and only help me through this. Support me"* (voice breaking).

It can be challenging for families who have a member who has breast cancer on how best to provide support while also managing their own emotions. The support provider has to learn to manage feelings in order to sustain a sense of control over the events (Thomas *et al*, 2010: 538).

Although, the emotional toll on women and their families can be anticipated, there are sometimes unexpected developments. As much as there may be stress and anxiety during the tackling of breast cancer, some women report some positive outcomes and changes occurring in respective spheres of their lives. There have been accounts where cancer patients have said that the cancer assisted in creating a deeper bond in social relationships with friends and family. Individuals had a new approach to life and new priorities, which can possibly translate into the daily activities for the patients (Schulz and Mohamed, 2004: 653).

4.6. Chemotherapy sessions and their impact

Chemotherapy made all the participants anxious, the majority of the participants reported a dislike for the treatment. The extreme fatigue and not feeling well caused distress for a lot of the participants. One woman describes her experience with chemotherapy.

“I find it [chemo] very hard. It is only my second time today and I am supposed to have four, they [doctors] have taken off the breast already. Chemo is very tiring; it is the worst.”

In contrast, there was a participant who had a different experience with her chemo, besides the fatigue, she had not felt anything else, her description was *“I have only had one and its been brilliant”*. However, she was also aware that her system could respond differently to the next chemotherapy sessions.

The fatigue and other side effects called for more assistance from family and friends and an understanding from the patients themselves that, they would no longer be able to perform certain activities, and they eventually have to embrace the assistance offered. The participant, who had a *“brilliant”* first session of chemotherapy, describes her difficulty with allowing people to assist her.

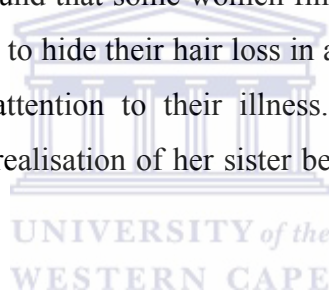
“The most difficult thing is allowing people to help me...I’m at my dream job at the moment and I am performing high, and then you get this [cancer] and then you go through chemo, and then you are so tired. And I am a person when doing an assignment, I prepare up until the last minute... I can’t do that now and adjusting, getting people to drive me around I can’t walk to places. It’s just a dependency level I have never ever had.”

The stripping of independence caused by breast cancer can be frustrating for women, who have to learn to rely on others for activities they were capable of doing. Although women may be in need of support, they may relinquish their rights of receiving it because of being socialized to be the caretakers in their households. As with the participant above, losing independence can be particularly challenging for some as they wrestle with when to ask and to allow for support. The providers of the support have to not overpower the women as this can possibly cause conflicts and resistance from the solicitors of the support.

Another woman explained how the chemotherapy had affected her physically. The physical changes caused her sister to become emotional. The participant had asked her sister to cut her hair as it had begun rapidly falling out. Although, she seemed unconcerned about her hair loss, her sister was crying during the haircut. The main concern for the woman was she did not want people talking about her and possibly making assumptions about her illness and this prompted her to wear a wig when she was out in public. I asked whether she spoke to her sister about her illness and she responded with:

“Not very much, but I know, I can see it’s touching her. But, I’m very positive. I’ll get through it.” (The participant began crying at this point.)

The answer above was full of the elements that are likely to cause many women to feel emotional. It has been found that some women find it difficult to cope with their hair loss. Others try their best to hide their hair loss in a bid to avoid being referred to as the ill one or bringing attention to their illness. The participant’s sister was probably overcome with the realisation of her sister being ill and the fears that come with that realisation.



A study conducted by Rasmussen *et al* (2010: 156) found that women who had cancer and had visible bodily changes would attempt to hide them by wearing wigs, certain types of clothing and wearing a prosthesis. The reasons given for going to such great lengths were to avoid being stared at, to be avoided by someone they know and to be met with a specific statement (Rasmussen *et al*, 201: 157).

In conclusion, during the six (6) months of attending the support groups and conducting interviews, my observations are that cancer is still very much a stigma in the minds of ordinary people. There were some individuals who were afraid to say that they had cancer. This was largely because they did not know what cancer is and they saw it as a death sentence. From the interviews, it was clear that there was a lack of knowledge and an abundance of misunderstandings about breast cancer. The participants were misinformed about who was at risk and at what age. Some of the reasons why individuals came to the support group were that they were seeking more

knowledge about their cancer. They criticized the doctors for being too clinical and/or not explaining enough when discussing the cancer. Additionally, others complained of the lack of support and empathy from the doctors. The individuals felt hopeless and frustrated, as they were still uninformed and/or misinformed about their illness. Furthermore, they were unable to convey useful information about their cancer to their families.

This chapter has described the findings and results. The conclusion and limitations of the study, as well as suggestions for future research and possible interventions, are discussed in the next section.



Chapter Five: Discussion and Conclusion

5.1 Discussion

The aim of this study was to present an account of social support provided by the families of women with early stage breast cancer. This entailed identifying and examining the types of support that women received; whether they found them beneficial or not, and if there were other forms of support they would like to receive from their families.

Social support is multi-dimensional, typically constructed from three dimensions that include: emotional, informational and instrumental support. A diagnosis of breast cancer can leave women feeling shocked, fearful and battling questions of why me? These are all common responses to the diagnosis of breast cancer according to Scott, Halford and Ward (2004:1122). The results showed how significant support can be for women who are confronted with such a healthcare crisis.

The results showed evidence of the three components of support that were identified- emotional, tangible and informational. According to Bloom, Stewart, Johnston, Banko and Forbair (2007:1516,1514), emotional support is *“the perceived availability of thoughtful, caring individuals to whom one can share one’s imminent thoughts and feelings and/or that one is loved and valued”*. In the participant’s accounts, the notion of being cared for was apparent in two ways, the first was the participants having someone to talk to and the second was someone being physically there for them. All the participants felt that they had someone that they could talk to about their emotions. Although all expressed having someone to speak to, others held back on using this resource to their full benefit and this was influenced by a desire not to ‘burden’ their loved ones with some of their fears and insecurities. There were some participants from the support group that couldn’t indulge in the benefits of having emotional support as some had not informed their families of their diagnosis and others had their families shun them.

The family members that made time to be physically present to the participants made them feel that they were not going through the cancer journey in isolation. One participant who particularly came to appreciate this was the thirty (30) year old, she spoke of frequent requests from family members and friends who desired to accompany her to chemotherapy sessions, she saw this as a way of them showing her that they are there for her and are supporting her.

Tangible (instrumental) support according to Bloom et al (2007:1514) is the specific resources that others may provide the individual such as a financial assistance, transport to the medical appointments and childcare. There were many participants who were grateful and took comfort in the physical availability of family and some friends who accompanied them to their appointments. Literature from Lugton (1997:1186) revealed the advantages of having individuals present during doctors consultations; the reasons given were some women find themselves overwhelmed by the information they received and thus having missed some of the details conveyed by the medical personnel. The people accompanying the women can also ask questions and/or seek clarification on the information given. The participants were highly dependent on the instrumental shows of support such as cleaning, transportation to and from appointments or food being prepared for them, especially after receiving chemo or radiation treatment.

Informational support refers to the provision of facts and information about the individual's illness. One participant who was able to receive this support at home was the 30-year-old participant whose mother had survived cancer, she often spoke to her mother about the side effects from the treatment and other information she was unsure of. In contrast; the literature revealed how some women do not appreciate this support from their families; they would rather they received it from specialists. Receiving informational support can be valuable to women diagnosed with breast cancer, as it can be a source of gathering new information about their illness. This is important as one found that some women had misconceptions about the risks and development of breast cancer. This was confirmed by Matatiele and Van den Heever (2008:69a) in that "many South African women generally have limited knowledge of their relative risk of developing breast cancer, of associated risk factors and of the diversity of potential breast cancer-related symptoms". The one method that seemed to work in

aiding the detection of a foreign lump for the majority of the women who participated in the study was self-examination of their breasts; one woman was encouraged by a visitor to her work to have a mammogram conducted. This is significant as it adds to the importance of breast self-examination and education of South African women about breast cancer.

The support group provided a mixture of information on the experiences of support for women diagnosed with breast cancer. There were women who were petrified of informing their families about their diagnosis from fear of a possible negative unknown reaction from their families, women also feared being the topic of discussion in their communities because of their illness. During the time I attended the support groups, there were very few women who had received positive support from their families and were happy. The presence of women who had positive support from family was significant, in that they were able to tell their stories of how they engaged their families and ultimately found a way of communicating with them about their illness, this was knowledge that others could possibly use in their homes.

A form of advice that was given by the group leaders, that one found controversial and did not align with some of the literature reviewed, was that family members should not show their emotions to the affected individuals. One can see how they may make such a conclusion as one participant was affected by her younger brother's crying; she felt that it made her weak. However, on the other hand, family not showing emotion has left some individuals thinking their family does not care and that they are expected to act in the same manner.

In a study conducted by Thomas et al (2010: 537) one woman found herself becoming annoyed with her husband because he was not showing emotion and she interpreted it as though she had to be strong even though she wanted to cry and be angry about her situation. Therefore one believes that the advice the group leaders gave could be altered in order to reflect a more neutral idea of how family members could possibly manage their feelings and those of the ill individual.

Cancer support groups can be advantageous for people who receive support from their families and for those that do not. Studies have found that cancer support group can have *“processes which are beneficial, including mutuality and cohesion, which act to instill a sense of hope, altruism, and universality, identification with others in the same situation, which leads to a sense of belonging and empathy; and the provision of cancer related information, which acts to improve coping”* (Ussher, Kirsten, Butow and Sandoval, 2005:2566).

Ussher *et al* (2005) have shown that cancer support groups provide a space where individuals can talk about topics which they feel they would not be able to discuss at home, one of these being death. Individuals were free to openly voice their fear of death and not to hide any of their emotions, as some felt that friends and family would do their best to avoid the topic or did not know how to respond. The support group also offered an environment where people could cry, voice their concerns and be able to communicate that they were “not okay” that day. This can be seen as beneficial as some do not have the opportunity to do so at home, many women expressed the need to be strong for their families and had very little opportunity to show their emotions. Therefore, although some individuals in the support group received support from their families, the group can provide *“a unique forum which facilitates talking safely, demystifying the unknown, deciding, hoping, and finding a separate space”* (Ussher *et al*, 2005: 2566).

5.2 Limitations and recommendations

The study was valuable in that it gave a brief overview of the type of support received by women with early stage breast cancer from their families. The benefits of support have been mentioned extensively throughout this paper. Furthermore, it attempted to address gaps in the literature dealing with breast cancer and the support available to poorer women in South Africa.

The shortcoming and limitations of this research pertains the number of people interviewed. I believe that one would have had a wider scope and variation of narratives that would have enriched the research, had there been more interviewees. Additionally, more revision and expansion of questions was needed, time was limited

with the participants and the altering of the topic, aims and questions, unfortunately had to be done on the spot, nevertheless this does not take away from what has been presented.

The recommendation for anyone who desires to conduct a similar study is interviewing individuals from different races and socio-economic statuses. It is also advisable to interview the same participants more than once, as there has been literature that has suggested that the support changes during some parts of the cancer journey.



5.3 Conclusion

The merits of social support to women diagnosed with breast cancer cannot be ignored. A cancer diagnosis can bring about significant distress and fear to the individual and their family. A structural change can occur as family members assume new roles and responsibilities in the home, all of this occurring while also managing emotions. The reality of families in South Africa being affected by breast cancer is increasing and thus looking at the family support to woman diagnosed with early stage breast cancer is significant as it can be used to inform families about what individuals need and start a dialogue between the individuals with cancer and their families.

This study aimed to identify the types of support afforded to women by their families, whether the women found it useful or not and other requests that they may have. Family support is crucial as these are the people that the individual spends most of their time interacting with and thus communication about what is needed from them is essential.

The types of support identified were emotional, tangible and informational. There was a strong prevalence of the first two types of support. All of the participants reported a general sense of satisfaction with the support that they received. This was significant as all of the participants were in their second round of chemo; this treatment can have serious side effects and thus a feeling of support can provide a sense of security and hope even during difficult times. I also attended a cancer support group at Groote Schuur and met a combination of women who received positive support from their families, others who feared revealing their diagnosis and others who had been isolated by their families. The support group offered a safe environment where individuals affected by cancer could speak about their experiences and thoughts without feeling judged, guilty or embarrassed. The group allowed for interaction that they would not necessarily have at home with family and friends.

This study aims to contribute to the limited information that we have in South Africa about social support for women with breast cancer. Considering the prevalence of the

disease and the potentially devastating impact on both individuals and society as a whole, this is a topic that should definitely be explored further as it can assist families on how to cope with breast cancer if they happen to be affected by it.



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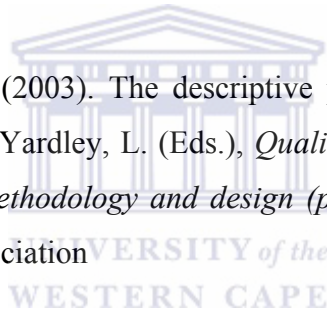
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Appendix A: Question sheet

Which age cohort do you fall into?

Are you married/have long term partner?

How long have you been together?

Are you employed/unemployed?

Is your spouse employed/unemployed?

Do you have children? Their ages?

When were you diagnosed?

What was your response?

Who was the first person you told, why?

Does your spouse know?, if not why? OR what was his response?

What things have you felt unprepared for?

What kind of things have been particularly difficult for you?

Does your (family member/s) do chores around the house? No, sometimes, often, all the time

Since the diagnosis, does your (family member/s) help with chores around the house? No, sometimes, often, all the time

Does your (family member/s) pick up your medication? (Is this by his own accord or you ask him to?)

Yes, No, sometimes, often, all the time

Does your (family member/s) accompany you to the hospital?

No, Sometimes, often, all the time

Have you asked your (family member/s) to accompany you to the hospital?

Elaborate

Do you talk to your (family member/s) about the cancer?

No, sometimes, often, all the time

Does your (family member/s) speak to you about the cancer?

No, sometimes, often, all the time

Does your (family member/s) ask how you are feeling physically?
No, sometimes, often, all the time

Does your (family member/s) ask how you are feeling emotionally?
No, sometimes, often, all the time



Appendix B



Consent Form

University of the Western Cape

A MICROSOCIOLOGICAL ANALYSIS OF SOCIAL SUPPORT TO WOMEN DIAGNOSED WITH EARLY STAGE BREAST CANCER.

Researcher: Thembekile Nokukhanya Kamanga

Please initial box

1. I confirm that I have read and understand the information sheet explaining the above research project and I have had the opportunity to ask questions about the project.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. (If I wish to withdraw I may contact the lead research at anytime)
3. I understand my responses and personal data will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the reports or publications that result for the research.
4. As a participant of the discussion, I will not discuss or divulge information shared by others in the group or the researcher outside of this group.
5. I agree for the data collected from me to be used in future research.
6. I agree for to take part in the above research project.

Name of Participant
(or legal representative)

Date

Signature

Name of person taking consent
(If different from lead researcher)

Date

Signature

Lead Researcher
(To be signed and dated in presence of the participant)

Date

Signature

Copies: All participants will receive a copy of the signed and dated version of the consent form and information sheet for themselves. A copy of this will be filed and kept in a secure location for research purposes only.

Researcher:

Supervisor:

HOD:



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DEPARTMENT OF RESEARCH DEVELOPMENT

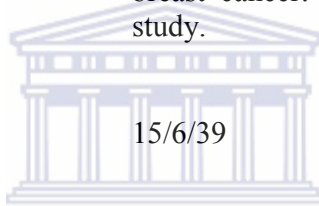
08 September 2015

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape approved the methodology and ethics of the following research project by:
Ms TN Kamanga (Anthropology & Sociology)

Research Project: A micro sociological analysis of spousal support to women diagnosed with early stage breast cancer: A Cape Town, South African study.

Registration no: 15/6/39



Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

The Committee must be informed of any serious adverse event and/or termination of the study.

*Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape*

A Microsociological analysis of social support to women diagnosed with early stage breast cancer

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