

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

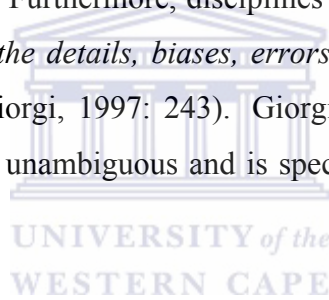
subject, *“instead of dividing it into parts without understanding the basic meaning structure, which gives sense to the whole experience”* (De Castro, 2003:47). If the prior is not taken into consideration, one faces the risk of talking about abstract concepts that do not represent or reflect the subjects 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

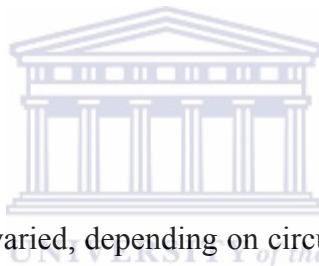
individuals usually accompanied them to their visits, or they deemed them as the closest person to them. One participant informed her brother first; when asked what his response was she responded:

“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.

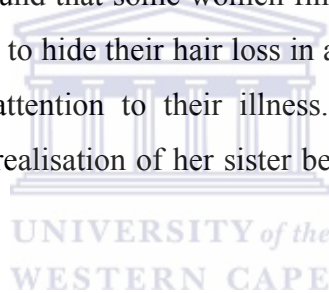
“The most difficult thing is allowing people to help me...I’m at my dream job at the moment and I am performing high, and then you get this [cancer] and then you go through chemo, and then you are so tired. And I am a person when doing an assignment, I prepare up until the last minute... I can’t do that 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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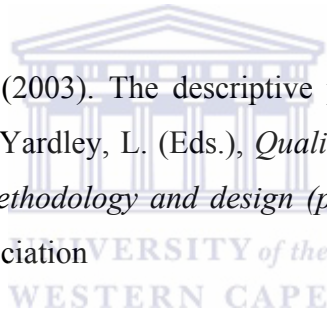
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Appendix A: Question sheet

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

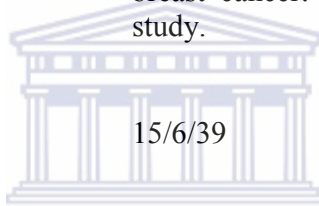
08 September 2015

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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