

Experiences of women in transition to survivorship following mastectomy in the Cape Metropole.

Nicole Elizabeth Stecher



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Supervisor: Mary A. Cohen

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DECLARATION

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ABSTRACT

Background: Breast cancer is one of the most common female malignancies worldwide and the cause of cancer death among women in developed and economically developing countries. The researcher, a professional nurse practicing in the operating theatre assisting with high volumes of breast surgery, identified a need to explore the needs of women following mastectomy as they transition into survivorship, in order to understand the challenges patients face after surgery.

Methods: A qualitative design with a descriptive phenomenological approach was applied, underpinned by Husserl' post-positive philosophy to elicit the participant's needs following mastectomy. Seven women who had undergone mastectomy for breast cancer and who resided in the Cape Metropole were selected by means of snowball sampling to participate in individual interviews. Consent to conduct the study was obtained from the Health Research Ethical Committee at Stellenbosch University and informed consent was obtained from the participants before each interview. Interviews took place at a location of the participant's choice, were audio recorded, transcribed verbatim and verified. The interviews were analysed thematically and the themes that emerged were emotional distress and individual coping mechanisms, concern for children and family, impact of changes to appearance and preferred support needs.

Results: Findings show that support requirements are based on the individual's psychological, physical and social needs. A need for breast cancer education and information in the individual's mother tongue was expressed.

It is suggested that women diagnosed with breast cancer should be educated along with their families in order to enhance the transition into survivorship.

Key words: mastectomy, support needs mastectomy, psychological experiences and mastectomy, body image, breast reconstruction, family support needs, cancer related fatigue, information avoidance, Xhosa culture and cancer, pain in mastectomy, phenomenology.

OPSOMMING

Agtergrond: Borskanker is die algemeenste maligniteit in vroue en die grootste oorsaak van kankerverwante sterfte in beide ontwikkelde en ekonomies ontwikkelende lande. Die navorser, 'n professionele verpleegkundige wat praktiseer in 'n operasie teater met hoë volumes van bors chirurgie, het 'n behoefte geïdentifiseer om die oorlewingsbehoefte van vroue na mastektomie te evalueer ten einde die uitdagings wat hulle in die gesig staar na chirurgie beter te begryp.

Metodiek: 'n Kwalitatiewe benadering met beskrywende fenomenologie is toegepas, vanuit post-positivistiese perspektief soos gepopulariseer deur Husserl, om die deelnemers se behoeftes na mastektomie te identifiseer. Sewe vroue vanuit die Kaapse metropool wat almal 'n mastektomie ondergaan het vir borskanker is deur 'n sneeubal steekproef geïdentifiseer om individuele onderhoude te ondergaan. Toestemming vir die studie is van die Menslike Navorsingsetiek kommitte van Die Universiteit van Stellenbosch verkry en ingeligte toestemming van elke deelnemer verkry voor die aanvang van elke onderhoud. Onderhoude het plaasgevind op 'n plek volgens elke deelnemer se voorkeur. 'n Klankopname daarvan is gemaak en na die tyd woordeliks oorgeskryf en geverifieer. Die onderhoude is tematies ontleed. Emosionele benoudheid, hanteringsmeganismes, kommer oor kinders en familie, die impak van veranderinge in voorkoms en voorkeure in ondersteuningsbehoefte was tema's wat na vore getree het.

Resultate: Daar is bevindings dat ondersteuningsbehoefte afhang van die individu se psigiese, fisiese en sosiale omstandighede. Die nodigheid van inligting en opvoeding in die individu se moedertaal is deurgans vermeld. Daar word voorgestel dat vroue wat met borskanker gediagnoseer word, saam met hul familie deeglike ingelig en onderrig ontvang ten einde die oorgang na oorlewing te vergemaklik.

Sleutelwoorde: mastektomie, ondersteuningsbehoefte in mastektomie, psigiese behoeftes en mastektomie, liggaam beeld, bors rekonstruksie, Familie ondersteuningsbehoefte, kanker-verwante moegheid, inligting vermyding, Xhosa kultuur en kanker, pyn en mastektomie, fenomenologie.

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CHAPTER 1:

FOUNDATION OF THE STUDY

1.1 INTRODUCTION

This chapter introduces the scientific basis for the study. Presented in this chapter are the rationale, significance, problem statement, research aim and objectives in addition to the methodology and ethical considerations.

1.2 RATIONALE

In the researchers' clinical experience perioperative nurses may not comprehend the challenges women experience following mastectomy. The researcher, a professional nurse in the operating theatre assisting with breast surgery, identified a need to explore and describe the experiences during the transition into survivorship of women following mastectomy in order to understand the challenges patients' face after surgery. Survivorship is defined by Knobf (2011:e6), as a distinct phase of care starting at the end of therapy and moving into the recovery phase following mastectomy. Savaddati and Levy (2009:71) describe survivorship as the period immediately following completion of treatment. It is a re-entry or a return to expected or usual life patterns.

These needs could contribute to meaningful care of these patients by healthcare professionals, employers, friends and family.

Literature reveals that female breast cancer is one of the most frequently diagnosed cancer and the leading cause of cancer death among women in developed and economically developing countries (Jemal, Bray, Center, Ferlay, Ward & Forman, 2011:69). Surgical treatment for breast cancer, mastectomy, is recommended with or without axillary clearance (Elder, Branberg, Björklund, Rylander, Lagergren, Jurell, Wickman & Sandelin, 2005:202). Cancer treatments and their successful outcome are determined by the extent of the cancer at the time of diagnosis (Edge & Compton, 2010:1471). Systemic therapy, also called adjuvant therapy, if administered after surgery, includes chemotherapy, hormone therapy and targeted therapy. Neoadjuvant therapy refers to systemic therapy given prior to surgery (Alteri, Barnes & Burke, 2013:24).

Responses by women during transition into survivorship, includes fears of the future, recurrence of the disease, feelings of loss, concerns about body image and self-concept, which relate to role adjustment and family responses (Knobf, 2011:e3).

1.3 SIGNIFICANCE OF THE PROBLEM

Breast cancer is one of the most dreaded and common female malignancies in the world. Approximately one in ten women in South Africa will be diagnosed with this disease (Hess, 2011:1). The prevalence and distribution of breast cancer in the Western Cape is 46.9% in the

mixed ancestry group, 42.9% in the white Afrikaner and 10.2% in the African Xhosa population (Schoeman, Appfelsteadt & Baaitjies, 2013:529,532).

For healthcare providers, knowledge of the patient's experience in the period of transition into survivorship could enhance their support and empathy of these patients. Through this study the support needs of women, following mastectomy, may contribute to meaningful holistic nursing care, recovery and adaptation of these patients and their families. The benefits of the study would be new knowledge generated with regard to the experiences within transition to survivorship of women following mastectomy in the Cape Metropole.

1.4 RESEARCH QUESTION

What are the lived experiences of women residing in the Cape Metropole, following mastectomy as they transition into survivorship?

1.5 RESEARCH AIM

The aim of the study was to explore and describe the lived experiences of women following mastectomy in the Cape Metropole as they transition into survivorship,

1.6 RESEARCH OBJECTIVES

- Explore the lived experiences of women who transition into survivorship following mastectomy.
- Describe the lived experiences of women who transition into survivorship following mastectomy.

1.7 RESEARCH METHODOLOGY

The research methodology applied to this study is briefly described here with in detail in Chapter 3.

1.7.1 Research design

A qualitative design with a descriptive phenomenological approach was chosen as the best method to explore and describe the participant's lived experiences as they transition into survivorship following mastectomy. Descriptive phenomenology is characterised by intuition, analysing and describing the findings (Spielberg, 1975, cited in Streubert Speziale & Carpenter, 2003:60).

1.7.1.1 Philosophical underpinnings

The post-positive philosophy of Husserl underpinned this study, who avers that reality is a creation of the individuals involved in the research and is therefore subjective (Nieuwenhuis, 2011:65).

1.7.2 Study setting

The study setting was neutral and private and its venue was left to the participant's choice (Grove, Burns & Gray, 2013:271).

1.7.3 Population and sampling

For the purpose of this study, the target population refers to women residing in the Cape Metropole, who have had a mastectomy for breast cancer. Seven participants were recruited for feasibility. Snowball or network sampling, a form of purposive sampling, was used to recruit participants. The Cape Town branch of Reach for Recovery assisted in this as gatekeepers to women with lived experience of mastectomy. Reach for Recovery is a national comprehensive non-medical programme who support women diagnosed with breast cancer and who have or are having treatment. They were asked to recruit willing participant's representative of women who live in the Cape Metropole. Names of four possible participants were provided by Reach for Recovery of which three participants of the final sample of seven were recruited. The remaining four participants were recruited via snowball/network sampling who were colleagues of the researcher, a breast surgeon and nurse. The researcher contacted the participants telephonically and explained the nature of the research and to enquire whether they would be willing to participate in the study. They agreed.

1.7.4 Specific sampling criteria

The inclusion criterion for this study was English-speaking women residing in the Cape Metropole who had a diagnosis of breast cancer, and had undergone bilateral or single mastectomy with adjuvant or neoadjuvant therapy.

1.7.5 Data collection tool: Interview guide

The researcher met with the organisers of Reach for Recovery where a discussion ensued regarding the challenges the participants face. The organisers of Reach for Recovery, of whom the volunteers have had mastectomies, suggested a semi-structured interview guide. The interview guide included an open-ended question that encouraged the participant to describe their lived experiences. Probing words based on the discussion at the meeting, were added to the interview guide in order to explore the individual's experience. The guide was further refined during the process of data collection and reflexivity by the researcher, to explore and describe aspects of the lived experiences of their transition into survivorship which appeared dominant in the previous interviews.

1.7.6 Pilot Interview

Following the meeting with Reach for Recovery, a pilot interview was undertaken with a participant who met the inclusion criteria for the study. This provided the researcher the opportunity to engage with the participant and to gain insight into the interviewing process. The data was rich and relevant to the study and is included in the findings.

1.7.7 Trustworthiness

The soundness of qualitative research is evaluated by its rigor or trustworthiness (Goldblatt, Karnieli-Miller & Neuman, 2011:390). Grove *et al.* (2013:58) note that rigor in qualitative research

is characterized by openness, adhering to the philosophical perspective, thoroughness in data collection, analysis and having self-understanding. Self-understanding is enhanced by the practice of bracketing and reflexivity. The researcher was aware of her worldview and epistemology, which relates to her picture or value stance in the world in order to protect against potential bias (Greeff, 2013:309). Prior to this study, the researcher's knowledge of mastectomy was limited to the surgical intervention. Guba and Lincoln (1985:316-323) propose four measures to ensure trustworthiness, namely credibility, transferability, dependability and confirmability.

A detailed explanation of how the researcher maintained trustworthiness is presented in Chapter 3.

1.7.8 Data collection

Interviews were conducted between 26 February and 1 July 2015 and each interview lasted between 30 minutes to one hour. Six participants were visited to verify the transcripts and to provide the opportunity for them to contribute further. The seventh participant was unavailable and requested the transcript to be sent to her via electronic mail.

Two recording devices were used at each interview to secure data in the event of equipment or power failure. The interviews were audio recorded, transcribed immediately and field notes were kept. The written materials are stored in a secure place and the electronic data is stored in a password protected electronic file and will be for 5 years. Field notes were kept and are attached to all transcriptions.

The interviews occurred at a venue of the participant's choice. As mentioned before, the researcher used a semi-structured interview guide. Each participant signed an informed consent in agreement of the interview and the recording thereof. The participant's name was not used in the transcription of the interview. Instead, they were coded numerically and successive interviews were separately identified alphabetically.

The researcher received training on qualitative interview skills at the University of Stellenbosch in a workshop organised by the Division of Nursing. It included reflection and summarising during an interview. It emphasized the importance of establishing a trusting relationship with the participants and of talking less and listening more. A detailed description is provided in Chapter 3.

1.7.9 Data management and analysis

The researcher audio recorded and transcribed the interviews verbatim. This entailed listening to the recordings a number of times. The data was analysed using Terre Blanche, Durrheim and Kelly's (2012:322) data analysis strategy for qualitative research. A detailed explanation of the management and analysis is described in Chapter 3.

1.8 ETHICAL CONSIDERATIONS

The importance of protecting the human rights of the participants at all stages of the research process was meticulously observed. Ethical approval (reference S14/11/266, Appendix A), was obtained on 13 February 2015, from the Health Research Ethics Committee of Stellenbosch University. The Committee ensures that the rights of the participants are protected, that the appropriate methods are used to gain informed consent and that the investigator conducts the research ethically (Grove *et al.*, 2013:183). Furthermore, informed consent was provided by the National Manager of Reach for Recovery following the researchers request for participants to be recruited from their pool of clients. Their concerns about the credibility of the researchers and the proposed study design, namely one-on-one interviews, resulted in an extensive discussion at the CANSA office in Mowbray Cape Town 11th March 2015. During the meeting a detailed explanation of the research study and ethical protocol required of the researcher and supervisor by the Health Research Ethics Committee of Stellenbosch University was explained. Consent was granted by the organisation to conduct interviews with their clients. The volunteer of Reach for Recovery, provided the names of four women who she had approached and who were willing to participate in this study. The researcher contacted three participants telephonically (the fourth participant was unavailable) to explain the purpose of the study and their potential involvement. At the first interview informed consent was obtained.

Thus all participants were fully informed of the nature of the study, initially telephonically and that they were under no obligation to participate or to continue with the interviews once they had begun.

1.8.1 RIGHT TO SELF-DETERMINATION

Self-determination relates to the autonomy and respect of the participant. The participant's, including the staff of Reach for Recovery, voluntary participated in the study and were not coerced or deceived. Each participant signed an informed consent to agree to join in the study, to the recording thereof and was free to withdraw at any stage without penalty.

The informed consent consisted of four elements, namely the disclosure of essential information, the comprehension by the participant and competence to agree and sign consent, including volunteerism (Grove *et al.*, 2013:177). In qualitative research, events and discussions could change during the study. Thus informed consent was an on-going and evolving process (Grove *et al.*, 2013:180), meaning that consent was obtained at each interaction during the research process.

1.8.2 Right to confidentiality and anonymity

The participants had the right to determine the extent, the time and the circumstances in which to share personal information. Information may be shared or withheld (Grove *et al.*, 2013:169).

Participants were informed that their names would not be used in the data and that a label would be allocated to the interview i.e. Interview 1, 1a. In addition, all data would be confidential and only

verified with the supervisor of the study. Participant verification or member-checking of data ensured the credibility of the data recorded and transcribed.

1.8.3 Right to protection from discomfort and harm

Creswell (cited in de Vos *et al.*, 2013:115) states that the ethical obligation of the researcher is to prevent harm. Grinnel and Unrau (cited in de Vos *et al.*, 2013:116) notes that beneficence is understood as maximizing benefits and minimizing possible harm. The researcher should ensure that the benefits of the study outweigh risk (Grove *et al.*, 2013:175). In addition, fair treatment is based on the principle of justice (Grove *et al.*, 2013:174). Benefits relate to health or psychosocial benefits as well as the contribution to knowledge (Grove *et al.*, 2013:175). Risks may be emotional, socially embarrassing or sensitive due to the nature of the topic (Grove *et al.*, 2013:174). In this study, the participants were assured of support from Reach for Recovery should they request it.

1.9 OPERATIONAL DEFINITIONS

Mastectomy: Surgical treatment for breast cancer surgery where the effected breast tissue is removed. Breast conserving mastectomy refers to partial mastectomy or a lumpectomy where only cancer tissue and a rim of normal tissue is removed. A simple or total mastectomy is the removal of the entire breast (Alteri *et al.*, 2013:23).

Rothrock (2007:582) defines mastectomy as the removal of the entire breast without lymph node dissection, whereas a radical modified mastectomy is the removal of the diseased breast tissue with axillary tissue.

Survivorship: According to Knobf (2011:e6), survivorship has been recognized as a distinct phase of care starting at the end of therapy and moving into the recovery phase following mastectomy.

Savaddati and Levy (2009:71) describe survivorship as the period immediately following completion of treatment. It is a re-entry or a return to the expected, or usual life patterns.

Adjuvant therapy: Systemic treatment for cancer used to treat undetected cancer cells. It is administered after surgery and is determined by the stage of the tumour stage and it's characteristics. Neoadjuvant therapy refers to treatment administered prior to surgery (Alteri *et al.*, 2013:24).

Reach for Recovery: an international comprehensive non-medical programme, providing a free and voluntary support group for women diagnosed with breast cancer during and after treatment.

1.10 DURATION OF THE STUDY

Ethical approval was obtained on 13 February 2015 and data collection was concluded on the 1 July 2015.

1.11 CHAPTER OUTLINE

Chapter 1: Foundation of the study

This chapter outlines the scientific foundation of the study. It includes a brief overview of the research, the rationale, methodology, philosophical underpinning, the research aim and objectives. Ethical considerations are described.

Chapter 2: Literature review

The literature review represents the current body of knowledge of the experiences of women in their transition to survivorship following mastectomy. This was modified according to the data gained during data collection.

Chapter 3: Research methodology

A detailed description of the research methodology applied in this study is explained.

Chapter 4: Results

Thematic analysis of data using Terre Blanche, Durrheim and Kelly's (2012:322) data analysis strategy for qualitative research, is described in this chapter, including interpretation and quotations from the interviews.

Chapter 5: Discussion, conclusions and recommendations

This chapter provides the discussion, conclusions and recommendations identified in this study.

1.12 SUMMARY

In Chapter 1, an introduction and rationale to the research study were described. The aim, objectives, research methodology, ethical considerations and philosophical underpinnings were outlined. Data collection and a brief description of the content of the following chapters were presented. Operational definitions were included.

1.13 CONCLUSION

A phenomenological enquiry into the lived experiences of the needs of women during their transition into survivorship following mastectomy for cancer was identified in order to improve healthcare provision.

Chapter 2 describes the literature that informed this study.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

The literature review is a presentation of relevant and current knowledge regarding a topic of study (Burns & Grove, 2011:189). A preliminary review provided a point of departure for the researcher to establish what is known or not known about the research problem. It entailed reading broadly and thereby developing an in-depth understanding of the subject matter (Botma, Greeff, Mulaudzi & Wright, 2015:63).

2.2 ELECTING AND REVIEWING THE LITERATURE

The preliminary literature review was conducted at the conception of the research purpose and the question for this study. It explored publications over the last ten years on the prevalence of breast cancer globally, the current treatment regimens and the effects of the treatment on women. Furthermore, similar or related studies that addressed the topic of this research study were explored, including the research paradigms and approaches used.

From the commencement of the data analysis, a further extensive appraisal of published literature took place to strengthen the review in line with the study findings. The review focused on the factors contributing to the experiences and the support needs of women following mastectomy. In total the following literature review took 21 months.

The search for literature was performed in databases such as: Stellenbosch University Library and Information Service, EBSCOhost, Pubmed, Science Direct, Wiley online and Google scholar. The American Cancer Society, and the Australian Cancer Council online websites were explored.

Keywords: mastectomy, support needs mastectomy, experiences post mastectomy, psychological experiences and mastectomy, body image, breast reconstruction, family support needs, cancer related fatigue, Xhosa culture and cancer, information avoidance, pain in mastectomy,

The literature review was based on thirty-seven articles, which comprised eleven qualitative studies, fifteen quantitative studies and eleven systematic literature reviews. Articles ranged from 2004 to current.

The literature search was refined according to the findings within the data after interviews. This included coping strategies, cultural challenges and family support needs.

2.3 PRESENTATION OF THE LITERATURE

The findings from the literature are presented in the following sequence:

- Female breast cancer
- Psychological impact of breast cancer;
- Psychological impact of altered physical appearance
- Pain
- Social impact of breast cancer and cancer related treatments
- Impact of cancer diagnosis on couples;
- Transition to Survivorship
- Quality of life in transition to survivorship
- Support in transition to survivorship
- Coping strategies in transition to survivorship;
- Coping strategy: Acceptance and positive re-interpretation;
- Coping strategy: Information Avoidance;
- Care in transition to Survivorship
- Family Support needs;
- Reach for Recovery Non-Profit Organisation

2.4 FEMALE BREAST CANCER

Female breast cancer is the most frequently diagnosed cancer and the leading cause of cancer death among women in developed and economically developing countries (Jemal *et al.*, 2011:69).

The prevalence of breast cancer in the Western Cape occurs in three predominant ethnic groups: mixed ancestry (half of population), Xhosa ethnicity (quarter of population) and the white Afrikaner and non-Afrikaner making up a quarter of the population (Schoeman *et al.*, 2013:529). Results reveal the distribution of the breast cancer genes to be 46.9% in the mixed ancestry group, 42.9% in the white Afrikaner and 10.2% in the African Xhosa population (Schoeman *et al.*, 2013:532).

The most widely used staging system to assess the stage of cancer is used by the American Joint Committee on Cancer (AJCC) with the most recent revision being the 7th edition, January 1st, 2010. The TNM system of codes relates to the extent of the tumour (T), regional lymph nodes (N) and metastasis (M) (Edge & Compton, 2010:1471). Mammography is currently most commonly used to detect breast malignancy due to its accuracy of assessing tumour size and borders (Pleijhuis, Graafland, de Vries, Bart, de Jong & van Dam, 2009:2720), whereas Magnetic Resonance Imaging (MRI), is effective in detecting ductal carcinoma.

Using wire-guided localization intra-operatively is a method of localizing breast tumours. By inserting a wire into the breast tumour under ultrasonography guidance, the tumour is located intra-

operatively. Once the lump is excised it is evaluated under mammography for localization of the tumour and calcifications (Pleijhuis *et al.*, 2010:2721). In addition, radio-guided occult lesions localization (ROLL) can be used to locate non-palpable tumours of the breast. A radioisotope is injected into the tumour under ultrasonography guidance. With the use of a hand held gamma probe intra-operatively, the tumour is located (Pleijhuis *et al.*, 2010:2724).

Furthermore, tumour margins can be assessed intra-operatively by frozen section analysis (FSA) (Pleijhuis *et al.*, 2010:2722).

Surgical treatment for breast cancer, mastectomy, is recommended with or without axillary clearance (Elder *et al.*, 2005:202). Breast conserving therapy (BCT), which includes a lumpectomy and irradiation therapy, has become the standard treatment for T1-T2 tumours. BCT offers a better cosmetic result, less infection risk and an improved emotional wellbeing than a mastectomy but has its risk with recurrence of cancer (Pleijhuis *et al.*, 2009:2717).

Psychological responses include fears of the future, recurrence of the disease, feelings of loss, concerns about body image and self-concept, which relate to role adjustment and family responses (Knobf, 2011: e3).

The researcher conducted a literature review on the possible psychological, physical and social impact of breast cancer and cancer related treatments on women following mastectomy.

2.5 PSYCHOLOGICAL IMPACT OF BREAST CANCER

The psychological distress of breast cancer diagnosis has a life changing effect on the individual. The effect on the family, choices of treatment, and changes to body image are some of the stressors that are faced. Furthermore, anxiety, depression, quality of life, fatigue, stress in daily living, including work productivity, can significantly affect the individual and their families (Nordin, Rissanen, Ahlgren, Burell, Fjällskog, Börjesson & Arving, 2012:2). Patients face fear and anxiety related to surgery, impairing and invasive treatments and the possibility of role and relationship changes (Helms, O'Hea & Corso, 2008:314). It was found that women diagnosed with breast cancer, suffered from self-depreciation, inadequate body image and weight gain (Helms *et al.*, 2008:319). Furthermore, the effects of surgery and treatment such as nausea, vomiting, pain and fatigue affected day-to-day activities in the family (Cebeci, Yangin & Teleki, 2012:407).

In addition, breast cancer is perceived by women as a life threatening disease and may lead to post traumatic stress disorder. Women who present with avoidance behaviour show a decreased ability in physical and social functioning (Nordin *et al.*, 2012:2; Vin-Raviv, Dekel, Barchana, Linn & Keinan-Boker, 2014:506).

Campbell-Enns and Woodgate (2015:113) note that women face their own mortality. Breast cancer threatens a women's self-integrity, which results in a restructuring of their lives and "meaning making."

Emotionally, some women prefer to be isolated from their family and friends. In addition, they report feelings of anger, depression, weakness and sorrow (Banning, Hassan, Faisal & Hafeez, 2010:307). Psychologically, the impact of the altered physical appearance was associated with perceptions of loss of femininity, which affected their relationships (Banning *et al.*, 2010:307).

Some women prefer not to inform the family of their diagnosis and visit homeopaths for treatment (Banning *et al.*, 2010:306). Moreover, some acknowledge that they ignored a breast lump for up to two years (Banning *et al.*, 2010:307; Knobf, 2011:e7).

Younger women experienced concern for their children whilst facing a life threatening disease. They had concerns for body image adjustment, sexuality, financial security related to career and work concerns (Manuel, Burwell, Crawford, Lawrence, Farmer, Phillips & Avis, 2007:86).

A study by Illingworth, Forbat, Hubbard and Kearny (2010:25), showed that women received encouragement to seek investigation from intimate and extended family relations. Relationships were considered a source of practical and emotional support. Moreover, the partner's interpretation and awareness of information played an important role in the patient's experiences related to cancer and cancer care (Illingworth *et al.*, 2010: 26). The safety found within relationships created an environment where responses to cancer could be shared.

Remmers, Holtgräwe and Pinkerton (2010:14) noted that women expressed their need to be listened to, in order to feel valued and cared for. Nurses needed to be more aware of the psychological and emotional needs of women in order to offer emotional support (Remmers *et al.*, 2010:13). Moreover, there is a need for trustworthiness, communication, privacy and professionalism from caregivers. Health care givers can enhance caring by recognizing the needs of women facing breast cancer and treatments (Remmers *et al.*, 2010:15).

2.5.1 Psychological impact of an altered physical appearance

The concept of body image is described as the level of investment women put into their body thereby helping them determine their well-being (Campbell-Enns & Woodgate, 2015:113). A disruption of body image can be affected by hair loss, weight gain and changes in the breast.

Boehmke and Dickerson (2006:1125) stated that altered body image and the loss of 'one self', effected personal identity, self-esteem, self-efficacy, interpersonal relationships and partnerships.

Helms *et al.*, (2008:321) noted that women's investment in body image and appearance may affect the choice of surgery and treatment when diagnosed with breast cancer. Women with a high investment in body image would choose a lumpectomy over mastectomy.

According to Helms *et al.*, (2008:319-320) hair is related to beauty, age, gender and maturity in society. Due to the effects of cancer related treatments, some women described loss of hair, including eyebrows, eyelashes, pubic hair and nasal hair as 'being erased' (Boehmke & Dickerson, 2006:1124), while others viewed their baldness as a sign of pride and courage (Boehmke & Dickerson, 2005: 385). Furthermore, hair loss that occurred in nostrils, caused nasal dripping, which women found distressing as they always appeared ill (Boehmke & Dickerson, 2005: 386).

Studies have shown that younger women seek normality in their breasts following mastectomy more often than older women (Campbell-Enns & Woodgate, 2015:113). Younger women found it more difficult to adapt to body image changes and had less adaptive coping styles. They were more concerned about their partner relationship and sexual functioning (Helms *et al.*, 2008:321). The anxieties of younger women in the study were more pronounced due to the stigma associated with breast cancer, life expectancy, implications for the future of their children and the need to inform inherited family.

A study in Sweden focused on women's experiences after mastectomy. Focal points were femininity, comfort with appearance, attractiveness to themselves and their partner, sexuality and relational comfort (Fallbjörk, Rasmussen, Karlsson & Salander, 2013:341). It was shown that women who had breast reconstruction with prosthesis were more concerned about their attractiveness. This resulted in greater dissatisfaction and moodiness postoperatively (Fallbjörk *et al.*, 2013:344). Furthermore, results showed feelings of decreased sexual attractiveness, accompanied by a decrease in their partner's interest sexually (Fallbjörk *et al.*, 2013:343). However, there was an improvement in overall body image two years post-surgery (Fallbjörk *et al.*, 2013:345).

A study in Taiwan revealed that women preferred a radical modified mastectomy to breast conserving surgery (BCS). The study showed that BCS led to a lower quality of life. This was due to treatment symptoms following surgery. However, it was noted that the younger, single and more educated women opted for BCS (Huang, Lien, Tu, Huang, Jeng, Chao, Sun & Chie, 2010:494).

In contrast, elderly women revealed no interest in breast reconstruction. There was an unwillingness to have 'more surgery' and face the possibility of complications. There was little concern over a 'new body' (Fenlon, Farnkland, Foster, Brooks, Coleman, Payne, Seymour, Simmonds, Stephens, Walsh & Addington-Hall, 2013:314). Although some women were not interested in wearing prosthesis, and accepted their body image, there were some elderly women who felt they were not ready 'to give up yet' (Fenlon *et al.*, 2013:312).

In addition Helms *et al.*, (2008:315) noted that about 80% of breast cancer patients suffer from weight gain due to adjuvant chemotherapy. Chemotherapy is believed to cause amenorrhea, which results in an accumulation and redistribution of body fat. Weight gain may also be associated with hormone therapy and psychological stress. Furthermore, the inability to express emotion may lead to over eating (Helms *et al.*, 2008:315).

The consequences of mastectomy over time, were shown to still affect women in their day to day lives. Reports have shown continued difficulty with weakness in the affected arm on the surgical side including scarring and lymphedema. Issues, such as difficulty in fastening a bra, due to restricted shoulder mobility are a challenge for the older woman. In addition to the challenges of breast cancer, co-morbidities in the elderly should also be taken into account (Fenlon *et al.*, 2013:315).

2.5.2 Pain

According to literature post mastectomy pain was a potential phenomenon experienced by women following mastectomy.

The perception of pain is different for every individual and may be influenced by certain factors. These factors include memory of pain, expectations of pain, culture, personality and behaviour and socio-economic aspects (De Menezes Couceiro, Valenca, Raposo, de Orange & Amorim, 2013:6).

Post Mastectomy pain syndrome (PMPS) is a common complication that may occur after partial mastectomy with axillary lymphadenectomy. PMPS starts postoperatively and may last for up to three months or more (de Menezes Couceiro *et al.*, 2013:1-2). A study in Brazil showed that 111 out of 250 selected women developed PMPS. The pain was experienced on the internal surface of the arm, anterior surface of the chest and in the shoulder of the surgical site. It was shown that PMPS was significantly associated with partial mastectomy and axillary lymphadenectomy (de Menezes Couceiro *et al.*, 2013:3).

There seemed to be a higher incidence of PMPS in younger women. This may be due to a poorer prognosis associated with younger women and related psychological distress. It was also shown that patients who regularly suffer from headaches tend to develop PMPS (de Menezes Couceiro *et al.*, 2013:5). It was recommended by the authors that a multidisciplinary team should be involved in the treatment of PMPS.

A study in Turkey revealed that participants experienced phantom pain following mastectomy where they felt as if their breasts were still there (Cebeci *et al.*, 2012:409).

Manuel *et al.*, (2007:92) noted that women best coped with pain symptoms and discomfort from pain by resting, taking medication and positive cognitive restructuring.

2.6 SOCIAL IMPACT OF BREAST CANCER AND CANCER RELATED TREATMENTS

On conducting a literature review the researcher found that a woman's culture potentially impacted her experience regarding breast cancer and cancer related treatments.

Culturally, it was found that Turkish women place great importance on their breasts. Breasts are seen as an organ of intimacy, nurturing and motherhood. In addition, breasts are seen as a sign of femininity and sexuality and play a role in self-identity (Cebeci *et al.*, 2012:407).

In addition, a Canadian study showed that South Asian women view the outline of their bodies as an important psychological issue when wearing ethnic outfits that outline the female figure (Ganz, Yip, Gralow, Distelhorst, Albain, Andersen, Bevilacqua, de Azambuja, Saghir, Kauer, McTiernan, Partridge, Rowland, Singh-Carlson, Vargo, Thompson & Anderson, 2013:611).

According to Banning *et al.*, (2010:307), stigmatization associated with breast cancer is prevalent in Pakistan. Pakistani women have shown strong cultural sensitivity toward female health, breasts, breast cancer and the association with self-breast examination. Banning *et al.*, (2010:304) found that there may be a reluctance to discuss breast health with daughters, female members of extended family or husbands or participate in breast cancer screening practices. In addition, there is a belief amongst Pakistani women, that breast cancer is passed on to an unborn child and therefore a mastectomy is the only option for treatment. These cultural issues and stigmatization illustrate the negative impact of breast cancer on the family (Banning *et al.*, 2010:306).

In addition, literature suggests that cultural barriers have a strong impact on breast health awareness. Asian women believe it taboo to 'touch oneself' and therefore do not practice self-breast examination. Moreover, they are embarrassed about discussing the intimate parts of the body or being examined by a male physician (Choudry *et al.*, cited in Banning *et al.*, 2010:304).

A study by Meneses and Yarbo (2007:107), identified cultural issues faced in South East and West Asia and Africa regarding breast cancer prevention. There were fears and misconceptions about breast health, examination and treatment. The study identified the beliefs that breast cancer is due to a curse from God, it occurs due to an injury of the breast, arises from immoral sexual activity, is fatal and only occurs in older women. A delay in seeking help was due to denial and the fear of gossip (Meneses & Yarbo, 2007:107).

High value is placed on the modesty of women in the Muslim culture. Women felt that breast cancer diagnosis was considered a threat to their being (Cebeci *et al.*, 2012:407), they expressed that they felt like 'half a person' after surgery and are useless as a woman without their breasts (Cebeci *et al.*, 2012:409).

Due to the data obtained from Xhosa-speaking women in this study, the researcher refined the literature search in order to gain insight into potential challenges faced.

A study in South Africa amongst a Colored and African community, revealed what women felt about the word 'cancer'. The study showed that cancer was associated with images of suffering and helplessness, and was accompanied by a death sentence (Mosavel, Simon & Ahmed, 2010:786). Women were not only concerned about death and the physical pain associated with cancer but they were concerned for the well-being of their families (Mosavel et al., 2010:791).

In addition, a South African study revealed that Xhosa-speaking patients felt socially isolated and regarded cancer as a killer disease and a curse (Lourens, 2013:109). Women expressed their fear of cancer and the difficulty in speaking about cancer due to stigmatisation (Lourens, 2013:113). Moreover, in order to protect their children they did not talk about cancer (Lourens, 2013:109). Xhosa-speaking patients needed to be encouraged to voice their fears concerning the illness (Lourens, 2013:115). The importance of traditional healers was emphasised where the ill tended to initially consult with traditional healers. When treatments were found to be ineffective, a Western doctor would be considered (Lourens, 2013:114). The study revealed that a patient's lack of understanding and fear of the unknown was linked to their decision to approach a traditional healer. This also influenced their compliance to cancer treatments (Lourens, 2013:116).

A lack of information regarding cancer diagnosis and treatment leads to misconceptions and has psychosocial implications on the family and affected family wellness (Lourens, 2013:109,110). Lourens (2013:110) pointed out the misconception that patients believed that radiation burns, cooks and destroys vital organs.

It was suggested that Xhosa-speaking patients suffering from breast cancer received information in their traditional language, to allow full understanding and reduce stress (Lourens, 2013:112). There was a need for oncology social workers to become part of the multidisciplinary team where diagnosis and treatment was communicated to Xhosa speaking women (Lourens, 2013:115).

2.6.1 Impact of cancer diagnosis on couples

A multi-cultural study at the University of Louisville, revealed that breast cancer treatment side effects were most stressful for couples (Kayser, Cheung, Rao, Chan & Lo Mphil, 2014:271). Asian couples showed more acceptance of the disease in contrast to American couples that focused on control and mastery of the problem (Kayser *et al.*, 2014:280).

In the Chinese culture, extended family played a role in support of illness (Kayser *et al.*, 2014:276). Although the family was utilized as a support structure, some couples revealed difficulty in balancing family involvement versus privacy and autonomy (Kayser *et al.*, 2014:277). Husbands were torn between caring for his wife, the parents and children. This dilemma was based on the Chinese tradition that emphasizes parent-child relationships and their obligation to their parents (Kayser *et al.*, 2014:278). In addition, conflict was experienced within the family with regard to treatment decisions (Kayser *et al.*, 2014:271). Moreover, the study revealed that Chinese women

had to consult their husbands with regards to doctor visits, treatment and mastectomy as this influenced family finances and the husband's view of his sex life (Kayser *et al.*, 2014:281). In contrast, American couples viewed treatment decisions as individual and in self-interest rather than in the interest of the family (Kayser *et al.*, 2014:281).

Americans viewed changes within the relationship as most stressful (Kayser *et al.*, 2014:271). Where Chinese husbands took over domestic roles, American husbands tended to employ professionals for the task (Kayser *et al.*, 2014:273). In view of American couples, the extended family was not involved in the cancer experience (Kayser *et al.*, 2014:278).

Indian women described how their husbands transcended their traditional roles in order to assist with responsibilities (Kayser *et al.*, 2014:279). Extended family also played a role in support of illness, although many Indian couples had to travel to the city for treatment and without their family (Kayser *et al.*, 2014:277).

Dobke, El-Khatib and Al-Basti (2012:430) explored multi-cultural experiences and controversies in breast cancer management. It was noted that the decision to undergo mastectomy is influenced by fear and non-evidence based factors such as family, belief and culture. In Islam, surgery is accepted as long as it is for the benefit of the patient, even if it 'changes the creation of Allah'.

2.7 TRANSITION TO SURVIVORSHIP

Savaddati and Levy (2009:71) describe survivorship as the period immediately following completion of treatment, when women transition out of the role of breast cancer patient to life as a survivor. It is a re-entry or a return to expected or usual life patterns. According to Knobf (2011:e6), survivorship has been recognized as a distinct phase of care starting at the end of therapy and moving into the recovery phase following mastectomy.

During therapy women have regular access to healthcare providers for support (Knobf, 2011:e5). Re-integration into everyday life proved to be a challenge since it was expected that they would return to 'normal'. Where normal is described as constant, average or routine, women found they were challenged within themselves to adapt to this concept. This was due to changes in self-concept from a personal, physical and social perspective after breast cancer. There is a recognized need for communication and supportive care interventions at the end of therapy during transition to survivorship (Knobf, 2011: e5).

The researcher interviewed women following mastectomy after they had been discharged from hospital care and were reintroduced into society and into their 'lives'. This period still included varied degrees of cancer related treatments, individual to the women interviewed. Women faced their illness without the day-to-day support from medical staff. Families became involved in the care and journey of their loved one. The researcher explored the challenges faced in this period.

A literature review revealed the possible needs and experiences of women during survivorship. Quality of life and support needs of women in survivorship are discussed. The researcher refined the literature search according to the findings following interviews.

2.7.1 Quality of life in the transition to survivorship

Quality of life was defined by the World Health Organisation Quality of Life Group as “an individual’s perception of his position in life in the context of the culture and value systems in which he lives and in relation to his goals, expectations, standards and concerns.” In addition, quality of life refers to a person’s subjective evaluation of his functioning in a wide range of areas (van der Steeg, De Vries & Roukema, 2008:1225).

Knobf (2011:e3) revealed that quality of life and psychological experiences were influenced by transitions experienced such as waiting for treatment, during treatment and after treatment. Patients tended to show increased anxiety in awaiting therapy, which appeared to decrease in a supportive therapeutic environment during treatment and increased at the end of treatment (Knobf, 2011:e4).

In the light of breast cancer, mastectomy and cancer related treatments, women may be unprepared for the expectations that await them. They experience loss when continued monitoring and support from medical staff ended and feared taking on the responsibility of self-monitoring (Allen *et al.*, 2009:75). Women struggled with the process of returning to family, work and social responsibility (Allen *et al.*, 2009:76).

Knobf (2011:e1) noted that one third to one half of breast cancer survivors reported unmet psychological needs, which influenced quality of life. Psychological responses included fears of the future, recurrence of the disease, feelings of loss, concerns about body image and self-concept which related to role adjustment and family responses (Knobf, 2011:e3; Allen *et al.*, 2009:76). Knobf (2011:e3) recognized that these psychological responses are expected in the face of breast cancer diagnosis, however persistent emotional distress may lead to maladaptive psychological responses such as reactive anxiety, depression or adjustment disorder.

In addition, quality of life was influenced by physical weakness and fatigue due to cancer treatments. ASCPRO (Assessing the Symptoms of Cancer using Patient-Report Outcomes) defined Cancer related fatigue (CRF) as the perception of unusual tiredness that varies in pattern or severity, which negatively impacts the functional ability of those who have cancer or who have had cancer (Barsevick, Cleeland, Manning, O’Mara, Reeve, Scott & Sloan, 2010:1088). Clinical trials measure CRF as a sensation of fatigue or tiredness, the impact of fatigue/tiredness on the patient’s life or as both the intensity and impact of fatigue. CRF is known to affect quality of life, functional outcomes, including work and possibly survival. It was stated that fatigue, distinct from many other symptoms is however not unique to cancer and its treatments (Barsevick *et al.*,

2010:1087). Wang and Woodruff (2015:447) noted that CRF negatively impacted the daily functioning of a survivor and lasted longer than typical fatigue. Its severity was overwhelming and caused patients to request a 'chemo holiday'. It was stated that chemotherapy induced various toxicities such as haematological, gastrointestinal tract and neural toxicities that may be a contributor to fatigue. De Nijs, Ros and Grijpdonck (2008:204) found that exercise had a significant effect on CRF, where patients who exercised experienced less fatigue. Furthermore, effects of chemotherapy included nausea, alopecia, menopausal symptoms, muscle and joint pain, and neuropathy (Boehmke & Dickerson, 2006:1123). In addition women experienced cognitive changes such as loss of memory and concentration as a result of chemotherapy. This was referred to as 'chemo brain' (Boehmke & Dickerson, 2005:386; Mitchell & Turnton, 2011: 545).

Furthermore, ethnicity and culture influenced the outcomes of quality of life for women with breast cancer. A study revealed that spirituality played a significant role in providing guidance, support and inner strength. In addition, a sense of coherence and hope directly influenced psychological well-being (Knobf, 2011:e8).

The 'pink ribbon' has become a global signature for breast cancer survivorship. Fifty-one percent of breast cancer survivors perceive themselves to be survivors where 49% reject this. Survivors were empowered since they had the strength to go through therapy and saw themselves as part of a larger group, whilst those who distanced themselves from the label, due to fear of recurrence, did not relate to survivorship (Knobf, 2010:e6).

2.7.2 Support in the transition to survivorship

Schmid-Büchi, Halfens, Dassen and van den Borne (2011:264), revealed that women one-year post medical treatment, still faced challenges related to cancer and its treatment. There was concern for the future, related course of illness, concern for family and relatives and fear of losing control. The main influencing challenges were treatment related symptoms that impaired their daily and social activities and altered their body image. Patients complained of symptoms such as hot flashes, fatigue, insomnia, joint and muscle pain, restriction of movement of the arm on the affected operative side and weight gain. This led to altered body image perception and impaired social and work activities (Schmid-Büchi *et al.*, 2011:263).

In view of psychological support, women received little support from the healthcare providers (Cebeci *et al.*, 2012:410). While the Turkish culture seemed to be fatalistic in their view of cancer, there was a strong sense of family. The women tended to receive most of their support from family and friends, who strengthened them in coping and decreased stress (Cebeci *et al.*, 2012:408). Worship also played a role in their management of breast cancer. The women felt worship was "good for my body, healing my disease and easing me" (Cebeci *et al.*, 2012:409).

Campbell-Enns and Woodgate (2015:114) stated that family relationships provided a high degree of social, emotional, tangible, informational and experiential support. In addition, some relationships were improved for breast cancer survivors.

Support groups have proved to have a positive effect on breast cancer patients. A study assessed the effect of counselling by specially trained nurses in the area of breast cancer. The nurse-counsellor groups showed great satisfaction with regard to issues discussed. Issues included, anxiety, information regarding cancer, prognosis, tests and contact with health care facilities (Nordin *et al.*, 2012:2).

2.7.3. Coping strategies in the transition to survivorship

Mollica and Newman (2014:334) state that the level of stress experienced by cancer survivors could be affected by the quality of their transition from patient to survivorship. This was dependent on the many characteristics of an individual and her environment.

Allen *et al.*, (2009:76) noted that women tended to engage in fear and threat reducing strategies in order to manage their health threat.

It was noted that individuals with absence or loss of meaning in life reacted to a life crisis rather than respond in a purposeful way (Jim, Richardson, Golden-Kreutz and Anderson, 2006:754). Jim *et al.*, (2006:753) noted that there were four dimensions to conceptualising the meaning of life. The first being feelings of inner peace and harmony, the second, feelings and thoughts of meaning and satisfaction with one's current and future life, the third being elements of spirituality or a belief in a purposeful pattern of the universe greater than that of the individual, and finally, the absence or loss of meaning in life.

In addition, social support and active coping helped individuals find meaning by engaging with others. Religious coping was thought to provide a framework of beliefs, which provided answers to the individual struggles (Jim *et al.*, 2006:754). Denial and avoidance were seen as negative coping strategies thought to interfere with adaptive thoughts and behaviours.

A study revealed that women's coping abilities were affected by physical factors such as fatigue and treatment symptoms, which affected their ability to maintain daily activities (Towsley, Beck & Watkins, 2007:100).

2.7.3.1 Coping strategy: Acceptance and positive re-interpretation

The most commonly used coping strategy identified was acceptance and positive reinterpretation, which re-evaluates the diagnosis as less negative and leads to a greater sense of meaning in life (Jim *et al.*, 2006:754).

Jim *et al.*, (2006:757) reveal that the way in which one copes with a cancer diagnosis predicted meaning in life. The search for meaning is important in the human experience. Cancer diagnosis can threaten previous perceptions about the meaning of life. Positive meaning can be associated with individuals who used positive coping strategies to change a negative life event into a more positive view. Where there was absence of positive coping strategies, individuals experienced feelings of loss (Jim *et al.*, 2006:759).

In addition it was noted that the woman's attitude and optimism could influence the onset of a coping mechanism in order to strive toward a new balance (Towsley *et al.*, 2007:102). Some women did not want to dwell on their cancer or discuss their condition (Towsley *et al.*, 2007:99).

2.7.3.2 Coping strategy: Information avoidance

Sweeny, Melnyk, Miller and Shepperd (2010:341) defined information avoidance as any behaviour intended to prevent or delay the acquisition of potentially unwanted information. Sweeny *et al.*, (2010:343) suggest three reasons for information avoidance such as (a) information may demand a change in belief where the positivity and consistency of self-views may be challenged, (b) information may include the state of one's health or life which may demand an undesired action or (c) information may be emotionally challenging in cases where decisions have to be made.

The emotional impact of information may lead to sadness, disappointment, fear, anger, embarrassment, guilt and shame (Sweeny *et al.*, 2010:344). Results from the study by Miles, Voorwinden, Chapman and Wardle (2008:1875) revealed that information avoidance could be associated with cancer fear, cancer fatalism, cancer severity, response efficacy and self-efficacy.

Moreover, Sweeny *et al.*, (2010:345) stated that information avoidance could be influenced by a loss of perceived control, having the resources to cope with information, the ability to interpret information and the expectations attached to information.

2.8 CARE IN TRANSITION TO SURVIVORSHIP

A study in Austria, part of the 5th Breast Health Global Initiative (BHGI) at the Global Summit, focused on survivorship care. Strategies in order to care more effectively for breast cancer survivors were identified (Ganz *et al.*, 2013:606). The recommendations included: the education of healthcare workers, patient and family education and community breast cancer awareness programmes (Ganz *et al.*, 2013:608,609). Attention to the psychosocial needs of breast cancer survivors and the availability of peer support groups and counselling is recommended (Ganz *et al.*, 2013:610). Furthermore, the need for a multidisciplinary team was evident and health professionals need to provide well-documented patient care records in order to facilitate the transition from active treatment to follow-up care (Ganz *et al.*, 2013:611).

A Train-The-Trainer (TTT) international breast health education program held at the University of Central Florida in Orlando, proposed to bridge the gap of a shortage of trained health care professionals. Professionals were needed to care and teach women regarding breast health and breast cancer in developing nations (Meneses & Yarbo, 2007:111). The TTT program imparted the most current knowledge regarding breast cancer screening, early detection, treatment, symptom treatment, social support and survivorship to nurses who have knowledge of different cultural beliefs and practices of women with breast cancer (Meneses & Yarbo, 2007:111). Furthermore, it was established that for health education to succeed it must fit into the sociocultural context of the patient's population (Lourens, 2013:117).

2.9 FAMILY SUPPORT NEEDS

The researcher conducted a further literature review as data emerged. The potential effects on the family of breast cancer and cancer related treatments were investigated.

Literature revealed that the burden and suffering experienced by relatives were influenced by how those relatives thought their affected member experienced the journey (Schmid-Büchi *et al.*, 2011:263).

The concept of family was viewed as a constant process of change. A definition of family was described by Whall (cited in Benzein, Hagberg & Saveman, 2008:108), as

“The family is a self-identified group of two or more individuals whose association is characterized by special terms, who may or may not be related by bloodlines or law, but who function in such a way that they consider themselves to be a family.”

Therefore the individual decides who is a member of the family, whether or not they are related.

Literature revealed that families are the preferred caregivers of their family member with cancer diagnosis. “Family” refers to spouses, partners, relatives or those identified by the patient as their family (McCarthy, 2011:429). The study indicated that families had information needs in taking care of their loved one. Information needs included, firstly, prognosis of the cancer. Families wanted time to prepare themselves and their loved one for the future. Secondly, information was needed with regard to cancer treatment, medications and their side effects in order to know how to assist their loved one. Thirdly, there was a need to know how hair loss and breast loss would affect sexual intimacy. The fourth need was related to knowledge and confidence in administering pain medications. This was due to a fear of overdosing or causing death. Families also needed information on the possibility of inheriting the disease (McCarthy, 2011:437).

In addition families had to actively seek information by accompanying their loved one to appointments, making appointments to see the healthcare provider, or approaching the healthcare provider themselves (McCarthy, 2011:437).

A South African study focused on cancer perceptions of mothers and daughters. Sixty percent of the daughters in the study revealed that their mothers never talked to them about cancer (Mosavel *et al.*, 2010:795). In addition, negative images regarding cancer were due to experiences of members with cancer within the community. Beliefs about cancer are localized within a family in a community context (Mosavel *et al.*, 2010:798). The authors propose that more focus should be placed on educating families.

Benzein *et al.*, (2008:107) noted that there has been a change in the health care system where healthcare is transferred from hospitals to patient's homes. As a result there is a demand for active participation by the family. Nurses found new ways of collaborating with patients and their families and created health-promoting conversations. It was noted that only family members themselves could narrate and interpret their situation. Nurses aided families by listening and establishing what priority needs were. This helped families develop a new reality (Benzein *et al.*, 2008:109). It was shown that family members found health-promoting conversations with nurses healing and comforting. Quality of family relationships were improved by an increased understanding of one another, confirming themselves as a person and strengthening their well-being (Benzein *et al.*, 2008:111).

A prerequisite for successful outcomes of conversations was for the nurse to be in partnership with the family (Benzein *et al.*, 2008:112).

2.10 REACH FOR RECOVERY NON-PROFIT ORGANISATIONS

Reach for Recovery was started in 1952 in the USA when Mrs Terese Lasser, a mastectomy patient, recognised the importance of 'being a survivor' in order to personally support women who had experienced breast cancer. This experience played a role in guiding women, diagnosed with breast cancer into the transition between patient and survivor.

Mrs Lasser visited South Africa in 1967 and Reach for Recovery was established shortly afterwards. South Africa was one of the first countries to establish a similar programme to the one that was launched in America. Reach for Recovery is now coordinated by the Queensland Cancer Council in Brisbane, Australia and is known as Reach to Recovery International (RRI). Reach for Recovery is thus affiliated to RRI, which is a comprehensive non-medical programme, created to help women with breast cancer. It is a self-help group based on the premise that former breast cancer patients, now physically and emotionally healthy can relate in a unique and positive way to new patients with breast cancer. Reach for Recovery is a free and voluntary support group.

2.11 SUMMARY

This chapter presents a literature review on lived experiences of women in transition to survivorship following mastectomy for breast cancer. The literature revealed that women following mastectomy are on a journey with their families in facing the challenges that breast cancer and its

treatments brings. They face psychological stress related to cancer diagnosis, concern for their families and changes in appearance due to surgery or treatments. Women need to be supported psychologically and physically. Literature revealed that the family, as defined by the individual, took on the hardships faced in this transition. Supporting and educating the family, regarding breast cancer, its treatments and possible side effects, better sustained the effected family member.

2.12 CONCLUSION

Literature reveals that the factors effecting the transition into survivorship are based on the individual support needs of women, which also translates into their individual coping strategies. Family support needs for education and information came to the fore as a necessity, which could greatly influence the transition of women into survivorship following mastectomy.

The following chapter focuses on the research methodology adopted to perform this study. A description of the design, method, data collection and analysis is provided. Measures taken to ensure trustworthiness and ethical considerations are explained.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 INTRODUCTION

The previous chapters described the background to the study and provided the literature review. This chapter presents a detailed description of the research methodology used in order to explore and describe the lived experiences of women following mastectomy for cancer in the Cape Metropole as they transition into survivorship. The design, population and sampling strategy, interviewing and analysis is explained. Measures to ensure trustworthiness are described.

3.2 RESEARCH METHODOLOGY

The research plan or methodology describes the process the researcher followed to explore the research problem or to answer the research question (Brink, Van der Walt & Van Rensburg, 2012:199)

3.3 AIM

The aim of the study was to explore the lived experiences of women following mastectomy for cancer in the Cape Metropole as they transition to survivorship.

3.3.1 Research Objective

The objectives set for this study were to:

- Explore the lived experiences of women who transition into survivorship following mastectomy.
- Describe the lived experiences of women who transition into survivorship following mastectomy.

3.4 STUDY SETTING

The study setting is the site or location used to conduct a study and in qualitative research is termed a natural uncontrolled, real-life environment (Burns & Grove, 2011:321). The location of the interviews, neutral and private was left to the participant's choice (Grove *et al.*, 2013: 271). The reason for this was the sensitive nature of the topic and the possibility that the participants would be more comfortable in a setting of their own choice. Most participants were interviewed in their homes. One participant chose to be interviewed at her place of work.

3.5 RESEARCH DESIGN

A qualitative design with a descriptive phenomenological approach was chosen as the most appropriate for the purpose of this study to explore and describe the lived experiences of women following mastectomy for cancer as they transition into survivorship. A phenomenological study

attempts to understand a person's perception, perspective and understanding of a particular situation (Delport, Fouche & Schurink, 2013:305; Grove *et al.*, 2013:60).

3.5.1 Philosophical underpinning

Phenomenology was defined by Husserl as a descriptive science of the essences and actions of consciousness. The researcher, when investigating a phenomenon as the lived experiences of the participant, uses the principle of intentionality. Therefore, there is a conscious focus toward an object (Sadala & Adorno, 2002:285). Husserl saw phenomenology as the starting point of all science where phenomena are focused on and described, and where the causal relations of the phenomena are searched (Sadala & Adorno, 2002:283). However, Grove *et al.* (2013:66) theorize that phenomena makes up a world of experience that must be described by the person experiencing it (Grove *et al.*, 2013:60). Nurses recognise the importance of phenomenology as a methodology in understanding the lived world (Sadala & Adorno, 2002:282).

The researcher identifies, records or documents lived experiences and chooses to set aside personal views (bracketing), in order to gain rich data (Grove *et al.*, 2013:60). The researcher, as an operating room nurse assisting with breast cancer surgery, has no current experience in the care of patients following surgery, having last worked in the wards many years ago as a student nurse. Her worldview about breast cancer and the transition into survivorship is limited to the media coverage and the discussions by surgeons during breast surgery. The researcher approached the study from a post-positivist stance. Ponterotto (2005:131) stated that post positivism advocates a modified dualism/objectivism where the researcher may have some influence on what is being researched. Objectivity and researcher-subject independence are important guidelines in the research process while being aware of biases and attempting to contain them (Ponterotto, 2005:132). According to Ponterotto (2005:130) a post-positivist researcher uses semi-structured interviews in order to identify a reality of collective experiences after consensual agreement of identified themes. In completing this study, the researcher gained access to the lived experiences of women following mastectomy in survivorship.

3.6 POPULATION AND SAMPLING

Grove *et al.* (2013:703) defined a population as all the elements (individuals, objects or substances) that meet the sample criteria for inclusion in a study, which is also referred to as the target population. The population in this study refers to women residing in the Cape Metropole, following mastectomy.

Snowball sampling, a form of purposive sampling, was identified as the best method of recruiting participants. Snowball sampling takes advantage of networking where current participants are able to identify potential participants with a similar experience (Grove *et al.*, 2013:366). Since the nature of the topic is personal and sensitive, Reach for Recovery, a non-profit organisation and

gatekeeper of multicultural breast cancer survivors, was approached to recruit potential participants.

According to Grove *et al.* (2013:371) and De Vos *et al.* (2013:391) the size of the sample depends on the depth and credibility of information required and or until data saturation is achieved (Grove *et al.*, 2013:371; De Vos *et al.*, 2013:391). Data saturation as agreed by Streubert Speziale and Carpenter (2003:25) refers to the repetition of information and confirmation of previously collected data. However, O' Reilly and Parker (2012:190) state that in the light of transparency and epistemology, data saturation in qualitative research is an inappropriate marker for quality. The authors argue that there is no singular way to measure quality due to its diversity (O' Reilly & Parker, 2012:191). Wray *et al.* (cited in O' Reilly & Parker, 2012:194) state that each life is unique and data will therefore never be truly saturated since new data always emerges.

Three participants were recruited via Reach for Recovery and four were recruited via professional colleagues of the researcher. The researcher became aware that each participant shared some similarities regarding cancer related treatments even though their personal experience was individual.

3.6.1 Inclusion criteria

Inclusion criteria also referred to as sampling criteria or eligibility criteria, include characteristics essential for the target population. Criteria are developed from the research problem, purpose, relevant literature, research design and the conceptual and operational definitions of the study variables (Grove *et al.*, 2013:352).

The inclusion criterion for this study was English-speaking women residing in the Cape Metropole who had a diagnosis of breast cancer, and had undergone bilateral or single mastectomy with adjuvant therapy.

3.7 PILOT INTERVIEW

De Vos *et al.* (2013:394) refer to a pilot study instead of a pilot interview. They recommend that in order to ensure the feasibility of the study, a pilot study can inform the researcher on the openness of the participants, their willingness to co-operate and the number of participants that could be involved until data saturation is achieved. Furthermore, they advise that a pilot study verifies whether relevant data can be obtained from participants with the same characteristics (De Vos *et al.*, 2013:394). Turner (2010:757) uses the term pilot interview that assists the interviewer with refinement of the research question.

In this study a pilot interview was carried out with the research supervisor present in the role of moderator. The interview was undertaken with a participant who met the inclusion criteria for the study. This provided the researcher the opportunity to engage with the participant and to gain

insight into the interviewing process. The data was rich and relevant to the study and was therefore included in the findings.

3.8 INSTRUMENTATION

The instrumentation used in this study refers to the researcher who collects and analyses the data by observing and interviewing participants (De Vos *et al.*, 2013: 65). In qualitative research the researcher is involved in perceiving, reacting, interacting, reflecting, attaching meaning and recording of data (Grove *et al.*, 2013:269).

3.8.1 Semi structured interview guide

By interviewing experts in the field, additional aspects, valuable to the study, were identified (De Vos *et al.*, 2013:395).

A semi-structured interview guide, including probing words, was developed based on the study objectives, the preliminary literature review and the organizers of Reach for Recovery. It was refined during the process of data collection (Grove *et al.*, 2013:274).

As guided by the interview with Reach for Recovery, the researcher used the following open-ended question after the initial introduction to the interview and after obtaining informed consent: "*Which events occurred that led you to discover that you have breast cancer?*" in order to assist the participant initially in sharing her lived experience.

The researcher encouraged the participant to share her experiences and guided her if needed in order to answer the research question which related to what her support needs were during survivorship (Appendix 3).

3.8.2 Interviews

Interviews are interactions between the participant and the researcher to produce data as words (Grove *et al.*, 2013:271). The researcher planned to conduct interviews until data saturation was achieved. The three recommended stages were to firstly to focus on the life history of the participant, secondly to acquire details of the phenomenon and thirdly to reflect on the experience of the participant (Grove *et al.*, 2013:271).

Rapley (2001:317) noted that interviews are economical in the sense of time and money and gain access to a topic where one has the opportunity to 'think out loud'.

According to Diccio-Bloom and Crabtree (2006:315), semi-structured interviews are organised around a set of open-ended questions while further questions emerge from the dialogue between the interviewer and interviewee. In addition open-ended questions are seen as invitation by interviewees to describe themselves and their experiences (Rapley (2001:309).

Moreover, Jarbandhan and Schutte (2006:678) state that semi-structured interviews are appropriately used when the researcher, certain of the research question, leaves room for exploration during the process of interviewing. Interviews on a descriptive level provide insights into the discursive nature of social reality, where on an exploratory level, interviews provide insights into the unexplored dimensions of the topic (Jarbandhan & Schutte, 2006:674).

In contrast to structured interviews, a semi-structured interview allows the respondent to be in control where the interviewer acts as a catalyst to the conversation (Jarbandhan & Schutte, 2006:675). Interviews should last between thirty minutes to an hour (Dicicco-Bloom & Crabtree, 2006:315). Rapley (2001:317) highlighted that the interviewer is a central and active part in the interaction. The interviewer's work should be viewed as central to the interaction, analysis and the presentation. Interview-talk was produced within a specific context and an awareness of that context is vital in understanding the talk, which relates to the data itself. The interactional nature of an interview causes data to be produced collaboratively (Rapley, 2001:318).

Discussions were electronically recorded. Two recording devices were used at each interview to secure data in the event of equipment or power failure. The researcher ensured that the participant consented to the recording of data (Grove *et al.*, 2013:272).

A verification strategy was used to attain trustworthiness of the study. The researcher met with the participants where they verified the transcription of the audio-recorded interview and were provided the opportunity to add more data. The participants agreed that the transcripts were true and accurately captured. All transcripts are stored in a safe place.

3.9 TRUSTWORTHINESS

The soundness of qualitative research is evaluated by its rigor or trustworthiness (Goldblatt *et al.*, 2011:390).

Grove *et al.* (2013:58) notes that rigor in qualitative research is characterized by openness, adhering to the philosophical perspective, thoroughness in data collection, analysis and having self-understanding.

Self-understanding is important in the interactive process of the researcher and is shaped by personal history, biography, gender, social class, race and ethnicity. Self-understanding allows the researcher to have insight into her own potential biases related to the phenomena of interest. Biases should be set aside in order to hear the voice of the participant (Grove *et al.*, 2013:59). Furthermore, in this study, three participants were recruited by Reach for Recovery and the remainder were recruited by snowball sampling. This sampling strategy guarded against recruiting bias.

Moreover, the researcher was aware of her worldview and epistemology, which relates to her picture or value stance in the world in order to identify potential bias.

Ontology refers to an assumption of the way reality is viewed. Behind this assumption lies theories or theories of knowledge and perception, and is known as epistemology. One's worldview is related to one's epistemological stance, "one's picture or value stance" in the world (De Vos *et al.*, 2013: 309). As stated previously, the researcher, an operating room nurse assisting with breast cancer surgery, had no current experience in the care of patients following mastectomy, having last worked in the wards many years ago as a student nurse. Her worldview about breast cancer survivorship was limited to media coverage and the discussions by surgeons during breast surgery.

The researcher approached the study from a post-positivist stance where the researcher, being aware of potential biases explored the experiences of women within their transition to survivorship following mastectomy using semi-structured interviews. Reflexivity was described by Grove *et al.* (2013:707) as being aware of one's self and the interaction between self and the data during collection and analysis. This may reveal aspects such as personal feelings and experiences that influence the study.

However, O' Reilly and Parker (2012:190) state that in the light of transparency and epistemology, data saturation in qualitative research is an inappropriate marker for quality. The authors argue that there is no singular way to measure quality due to its diversity (O' Reilly & Parker, 2012:191). Wray *et al.* (cited in O' Reilly & Parker, 2012:194) state that each life is unique and data will therefore never be truly saturated since new data always emerges.

Lincoln and Guba (1985:316-323) proposed four measures to ensure trustworthiness, namely, credibility, transferability, dependability and confirmability.

3.9.1 Credibility

Credibility refers to the authenticity of data. The researcher demonstrates that the subject was accurately identified and described (De Vos *et al.*, 2013:420).

The researcher, as recommended by De Vos *et al.* (2013:359) ensured that the researcher's interpretation of the transcripts matched the participant's views in order to enhance credibility. The participants verified the transcripts. Furthermore, the researcher's supervisor verified the data having been present at three interviews and listened to the audio-recordings while reading the transcripts of the other participants. In addition, the researcher wrote field notes immediately after each interview. Field notes enable the researcher to remember certain points and the process of the interview. In addition field notes are a written account of what the researcher hears, sees, experiences and thinks about during the interview.

3.9.2 Transferability

Transferability refers to the level at which the study is applicable in another setting. A thick and rich description of the phenomenon must be provided to enhance transferability (Wahyuni, 2012:77). In addition, Lincoln and Guba (1985:316-323) state that the researcher needs to provide a 'thick description' of the researched content and phenomenon, which relates to the views, processes and experiences of the participants. This allows others to assess the transferability to another setting (Ritchie & Lewis, 2003:268).

The researcher, in order to enhance the transferability of the study, ensured that all interview recordings were transcribed verbatim. As suggested by Ritchie and Lewis (2003:269) rigor in transferability is based on the accuracy with which the phenomenon was captured and interpreted in the study sample. In addition, the researcher as suggested by Ritchie and Lewis (2003:269), wrote field notes after each interview to enhance the quality of the data elicited and analysed the data thematically. The quality of the data is linked to the quality of the field notes, data analysis and interpretation. In addition, field notes were written after each interview in order to reflect on biases and potential probes that were missed during the interview. Field notes allow the researcher to document what was experienced, seen or heard during the process of the interview. It allowed the researcher to more accurately account for the data gained. The researcher was aware of her emotional stance at times during the interviews in order to ensure that she maintained objectivity.

Furthermore, Ritchie and Lewis (2003:269) note that due to the small samples used in qualitative research, the sample is not statistically representative of the population. Qualitative research focuses on a range of views, experiences and phenomena and the circumstances that shape them. This can be inferred to the research population. Moreover, it is the degree to which the sample is representative of the population sampled (Ritchie & Lewis, 2003:269).

3.9.3 Dependability

The researcher ensured that the research process was logical, meticulously documented and auditable (Schurink, Fouche & De Vos, 2013:420).

The researcher as suggested by Wahyuni (2012:77) provided a detailed explanation of the research design and a step-by-step explanation of the research process so that the reliability of data is enhanced (Wahyuni, 2012:77). As previously mentioned, all interviews were recorded, transcribed and stored in a safe place. In addition, field notes were kept and attached to all transcriptions.

3.9.4 Confirmability

Confirmability relates to the extent with which findings can be confirmed. Results should reflect the understandings and experiences of the participants. This can be enhanced by peer assistance in cross checking the coding and themes in analysis (Wahyuni, 2012:77). In addition confirmability

captures the concept of objectivity. The researcher provides evidence that confirms the findings and the interpretation by auditing (Schurink *et al.*, 2013:421).

The researcher maintained an audit trail of the research process, which included the interactions with the participants. This was a systematic process of documentation that described what was discovered and how it was discovered. Furthermore, it provided an analysis of all decisions and actions taken during the research (De Vos *et al.*, 2013:422).

3.10 DATA COLLECTION AND MANAGEMENT

In qualitative research the researcher is involved in perceiving, reacting, interacting, reflecting, attaching meaning and recording of data (Grove *et al.*, 2013:269). The researcher interviewed seven participants after obtaining ethical approval from the Health Research Ethics Committee and informed consent from the participants. Interviews are interactions between the participant and the researcher to produce data as words (Grove *et al.*, 2013: 271). Furthermore, Groenewald (2004:15) notes the importance of field notes as a secondary data storage method in qualitative research. Field notes comprise observational and theoretical notes where the researcher 'attempts to derive meaning' during reflection on experiences. Methodological notes are where the researcher points out reminders to self (self-critique) during the research process.

Ethical considerations for the study included:

- Approval from the Health Research Ethics Committee of University of Stellenbosch.
- Informed consent from participants
- Voluntary participation
- Confidentiality of participants during interviews
- Anonymity of data
- Beneficence and non-maleficence
- Weigh the risks and benefits of the study
- Storage of raw data and results in locked cabinet and on a password protected computer and retained for 5 years

After obtaining ethical approval by the Health Research Ethics Committee of The University of Stellenbosch, participants were recruited by snowball sampling. Reach for Recovery referred women who were willing to participate in the research study. Three of the participants were recruited via Reach for Recovery. Colleagues referred the remaining four participants.

Participants were contacted and the nature of the research study was explained to them. The researcher met with the participants at a venue of the participant's choice, which were mostly in their homes. The interview with Participant 6 occurred at her place of work.

The participants signed informed consent and understood that they could refuse to continue the interview at any time without penalty. Confidentiality was upheld as the participant's name was not mentioned in the transcription. Questions posed were semi-structured and organized around a set of open-ended questions as recommended by Grove *et al.* (2013:271). The participant verification strategy was used to attain reliability, validity and rigor of the study.

The researcher met with the participants for a second interview and verification of the initial transcribed interview. The participants verified the transcription and were free to provide additional information. Any additional information was recorded and a new consent form was completed. Most of the participants did not add new data to their experiences. The transcriptions are filed and stored. Participant 6, was unable to meet for a second interview and therefore accepted the transcription via email as agreed.

At the transcript verification visit with Participant 3, the family introduced themselves to the researcher. The participant's younger sister who lives with the participant, shared her experience in coping with her older sister's diagnosis. This was unplanned and the researcher decided to interview and record the family's discussion in the event it may shed light on the phenomena. The researcher asked Participant 3 for permission to record the conversation and if the need arose for the researcher to use her sister's contribution. Formal written consent was then obtained at the third meeting for the verification of the transcript. This information proved to be useful since the researcher discovered that families need support since they are the ones who ultimately care for the patient during survivorship.

Due to the cultural challenges faced in the Xhosa-speaking community as explained by Participant 6, the researcher identified the need to interview Participant 1 again to elicit whether she faced similar challenges regarding breast cancer in the Xhosa-speaking culture.

The following table represents data collection and verification of data by the participants.

Table 3.1: Participant biographic data and interview schedules

Participants 2015	Age	Race	Occupation	Interview Date	Interview with data Verification
Pilot interview	49	African	Professional nurse-Matron	(a) 26 Feb 2015 (b) 20 August, 2015b	13 May 2015 26 August 2015
Interview 2	52	Caucasian	Clinical nurse facilitator	20 march 2015	15 April 2015
Interview 3	42	Asian	House wife	(a)1 April 2015 (b) 18 April	18 April 2015 4 June 2015
Interview 4	52	Caucasian	University Librarian	22 April 2015	4 June 2015
Interview 5	58	Colored	House wife	7 May 2015	4 June 2015
Interview 6	34	African	Quantity surveyor /engineer	20 May 2015	1 July 2015

Interview 7	50	Asian	Special needs teacher	12 June 2015	1 July 2015
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3.11 DATA MANAGEMENT AND ANALYSIS

Erlingsson and Brysiewicz (2013:96) describe qualitative data management and analysis as the researcher's attempt to explore and describe the holistic and dynamic aspects of human life. The researcher presents the data in the context of the participant's experience, a world unique to them.

However, Groenewald (2004:17) argues that data analysis should be replaced by explicitation of data, which means that the constituents of the phenomenon investigated are kept whole. In addition the validity and truthfulness of the study is enhanced by the researcher "bracketing" assumptions in order to contribute to true findings (Groenewald, 2004:21).

According to Rapley (2007:126-132), the researcher should consider the initial research question during data analysis and refer to the research diary where all decisions, analytical thoughts and reflections were recorded throughout the process. Data should be transcribed in full and re-examined in order to become thoroughly familiar with it. The researcher should be fully attentive to words and phrases from the participants' vocabulary in order to capture meaning. Different themes, topics or codes should be identifiable in the analysis of each interview transcription. As themes are identified the researcher looks for underlying similarities between them as well as for deviations from the norm.

In this study thematic data analysis was carried out according to Terre Blanche, Durrheim and Kelly's (2012:322) strategy for qualitative data analysis.

Step 1: Familiarisation and Immersion

Data analysis in qualitative research includes becoming immersed and familiarised within the data, transcripts and field notes.

Step 2: Inducing themes

This step refers to organising the raw data gained from the transcripts and categorising principles that naturally occur in the data. Categories or themes are developed (Terre Blanche *et al.* 2012:323).

Step 3: Coding

Coding refers to the reduction of data into labelled meaningful pieces which are later clustered to develop themes (Terre Blanche *et al.*, 2012:325). Coding entails highlighting a phrase, a line, or a paragraph that pertains to the theme under construction (Terre Blanche *et al.*, 2012:324). A suggested method of coding is to use a cut-and-paste function in order to assign text to themes under construction (Terre Blanche *et al.*, 2012:325). Terre Blanche *et al.* (2012:326) suggests that

themes and codes blend into each other as the process of coding develops. Themes may change during the process of coding as the researcher gains a deeper understanding of how they relate to other themes.

Step 4: Elaboration

Elaboration is the process of examining the developed themes more closely in order to refine the data captured and to elicit deeper meaning from data (Terre Blanche *et al.*, 2012:326). During elaboration one can revise the coding system and thoroughly analyse the data until no new significant data appears.

Step 5: Interpretation and checking

The interpretation of the phenomenon will be presented as a written account developed from the themes developed during analysis (Terre Blanche *et al.*, 2012:326).

The researcher during this process reflected on her role in data collection and the interpretation thereof.

Following transcription of audio recorded interviews, the researcher became immersed in the data in order to reduce data by means of coding. The researcher cut and pasted the transcribe interview into a two-column Microsoft Word table. Following this, the researcher identified codes from the data of statements that had meaning within the phenomena as described by the participants. Common codes were grouped together and themes were allocated. The researcher printed and cut out grouped codes and themes, which were pasted on a wall within categories such as, for example, physical and emotional needs (Appendix 6). The researcher compared themes amongst the data and recorded common themes as findings.

3.12 SUMMARY

After receiving ethical approval a descriptive phenomenological study exploring and describing the lived experiences of women following mastectomy in the Cape Metropole as they transition into survivorship was conducted. Interviews were conducted in a setting chosen by the participant after obtaining informed consent. The interviews were recorded, transcribed verbatim and verified with the participants. The data was analysed using thematic analysis according to the steps suggested by Terre Blanche, Durrheim and Kelly (2012:322).

3.13 CONCLUSION

Chapter 3 described the methodology which was applied to this study. Chapter four will detail the analysis of the data and the interpretation of the findings in this research study.

CHAPTER 4: FINDINGS/RESULTS

4.1 INTRODUCTION

The previous chapter described the methodology used in this study which explained the meticulous process of attaining trustworthy findings. Themes that emerged from the interviews are presented in this chapter. Data analysis was conducted according to Terre Blanche, Durrheim and Kelly's (2012:322) five steps, which shaped the themes presented in this chapter. In order to orientate the reader to each participant in this study, the participants' profiles are outlined followed by themes and categories that emerged from the phenomenological data collected during the interviews.

The findings will be presented in a narrative format.

4.2 SECTION A: BIOGRAPHICAL DATA

The following biographical data represents the participants of the study interviewed in the Cape Metropole regarding their experiences following mastectomy for cancer.

All the participants were initially contacted telephonically to explain the study and to verify that the participant was willing to be interviewed. On first meeting the participants, the researcher introduced herself and stated the objectives of the research study. The participants read and signed informed consent and were informed that they were under no obligation to share if they felt uncomfortable in any way.

Following are the data pertaining to the participants interviewed.

Participant 1 is a 49-year old, single African woman, mother of one daughter and a Professional nurse. She had a wide excision of a tumour on her right breast and symmetrising procedure to the left breast. She was interviewed one-year post surgery in a homely setting familiar to her. She appeared relaxed and shared her experiences fully. Due to the data gained regarding the challenges faced within the Xhosa culture relating to breast cancer diagnosis and treatments, the researcher met with the participant for a second interview where additional written consent obtained. The interview was recorded, transcribed and emailed as requested by the participant for verification. During the second interview the participant said she planned to start a support group for breast cancer patients in the residential area in which the hospital that employs her is situated.

Participant 2 is a 52-year old, married Caucasian woman, mother of one son and a Clinical Nurse Facilitator. She had a left breast mastectomy with prosthetic reconstruction. The participant was interviewed at her home. Even in the light of her surgery being 10 years ago at the time of the interview, she clearly remembered her experiences. The participant continues to offer emotional

support to women who undergo mastectomy. The participant verified the transcript of the interview during a second visit.

Participant 3 is a 42-year-old married Asian woman, mother of one daughter and a housewife. She had a mastectomy of the right breast with no prosthetic reconstruction. The interview took place one-year post surgery in her home. The participant appeared nervous to share initially but shared freely later. Upon verification of the transcript at the participant's home, the participant's family who supported her joined in and met with the researcher. The participant's sisters shared of their experiences in relation to their sister's diagnosis. The researcher requested permission to record what the sister of the participant shared which was followed by Informed Consent provided by Participant 3 to use the data if needed. The transcription was verified and the data was useful in the findings that related to the support needs of families.

Participant 4 is a 52-year old, married Caucasian woman, mother of two children and a university librarian. She chose a bilateral mastectomy instead of a single mastectomy for symmetry in appearance. She was interviewed one-year post surgery at her home. She had reconstructive surgery two days prior to the interview, where her volume expanders had been removed and she received her prosthesis. She still carried a drain. She was on leave and preferred to be interviewed during that time. The participant appeared positive and friendly and offered tea and brownies to the researcher and accompanying supervisor. She freely spoke of her experience and sounded strong. She based her 'blessed' year on her faith, support from friendships as well as her students. The participant verified the transcription of the interview during a second meeting.

Participant 5 is a 58-year old, married Colored woman, mother of two children and a house wife. She had a left breast mastectomy with no prosthetic reconstruction and was one-year post surgery at the time of the interview. Participant was very open and humorous regarding her experience. She received most of her support from family and her neighbour. She expressed her gratitude in having an opportunity to share her experiences. The participant verified the transcription of the interview during a second meeting.

Participant 6 is a 34-year old, married African woman, mother of two children and a candidate quantity surveyor. She had a right breast mastectomy with prosthetic reconstruction and a symmetrising procedure of the left breast. At the time of the interview she was one-year post surgery. The researcher was not familiar with the suburb in which the participant resided. Since the participant was back at work and due to time and availability constraints, the interviewed took place at the participants work location in the City of Cape Town. Two couches were available in an area created for conversation. Even though there were times that colleagues passed by, the conversation was interesting and remained focused. The participant was open about her experiences after diagnosis of breast cancer, and her family's reactions. She mentioned cultural issues within the Xhosa-speaking culture regarding breast cancer. Issues included traditional

healing versus medical treatment/surgery. She voiced her wish to educate Xhosa women. The participant verified the transcription of the interview via email as requested, since she would not be available due to a work project.

Participant 7 is a 50-year old, married Asian woman, mother of two daughters and a special needs teacher. She had a left breast mastectomy with no prosthetic reconstruction. The researcher initially met with the participant in order to explain the research study and to agree to an interview date. The researcher felt grateful for the opportunity to see special needs children in their class environment and to gain a sense of the participant's specialty in her field. The participant chose her classroom office as the interview setting. At the time of the interview she was one-year post surgery. The researcher felt that the interview flowed. It seemed as if the participant needed to share her experiences as she experienced difficult challenges in her journey. She expressed her thanks to the researcher for the 'therapy'. The participant verified the transcription of the interview during a second meeting.

4.3 SECTION B: THEMES EMERGING FROM THE INTERVIEWS

The following table illustrates the themes and subthemes that emerged from the interviews.

Table 4.1: Themes and sub-themes

Themes	Sub-themes
4.3.1 Psychological experiences	Emotional distress Concern for family and children Coping strategies were Acceptance Being positive Information avoidance
4.3.2 Physical experiences	Psychological impact of changes in appearance
4.3.3 Social experiences	Making changes Cultural impact of breast cancer
4.3.4 Support needs in the transition to survivorship	Psychological support from family and friends Physical support needs Support needs of affected family Support groups

The objectives of the study were to explore and describe the lived experiences of women following mastectomy as they transition to survivorship.

The following themes emerged:

Women had **psychological needs** as they experienced shock when diagnosed with breast cancer; found it stressful to share diagnosis with their families and showed a concern for their children. Findings revealed that women developed coping strategies in the face of breast surgery and the effects of treatments. In addition women experienced psychological stress due to the challenges faced in coping with an altered body appearance for example breast loss and hair loss.

Women also suffered from the **physical effects** of cancer related treatments and cancer-related fatigue.

The **social needs** of women following mastectomy were also identified. Due to the importance of appearing normal in society women made changes such as wearing a breast prosthesis for symmetry. Culture also played a role in the understanding of mastectomy and treatment. For example the African women felt isolated by their breast cancer diagnosis because cancer is not talked about within their community.

By exploring the experiences of women following mastectomy in the Cape Metropole the research purpose was to identify support needs in the transition to survivorship. The researcher developed further themes in relation to the psychological, and physical support needs of women following mastectomy in the survivorship period.

4.3.1 Theme 1: Psychological experiences

Theme one, discusses three sub-themes namely, Emotional distress, Concern for family and children and Coping strategies.

Emotional distress, related to the psychological experiences of women following breast cancer diagnosis. Findings illustrated the emotional distress women experienced upon breast cancer diagnosis where one participant expressed that she felt “*shell shocked, it feels as if someone has actually kicked you*” P2, while another felt an urgency for the cancer “*to be taken away from me.*” P3.

Furthermore a participant articulated her experience as a life-altering event,

“...and you sit in doctor’s room and sit in waiting rooms and so...and life is just going by. Everything is just completely normal on the outside and that actually um, that affected me quite badly, you know having been, where your life changes just within that one day or.... I saw somebody walk past with a cool drink and a packet of chips and I just thought to myself, you’re walking here with a packet of chips and a cool drink like nothing is happening.... I was that person a few days ago...” P7.

Remmers *et al.* (2010:13) noted that women, when diagnosed with breast cancer felt shocked and were suddenly faced with their own mortality. They questioned their ability to cope with the disease, their reaction to it and its challenges.

Moreover, *concern for family and children* were found to be a challenge for women psychologically after diagnosis with breast cancer. Remmers *et al.* (2010:13) noted that women’s burden for their families included wanting to protect the family from the severity of information regarding breast cancer diagnosis. Women confessed that they felt more concerned for their families than for

themselves and felt a need to console them. In addition they feared becoming a burden to their families.

Findings revealed the need for women to protect their families. One participant shared that she kept information from her husband initially: “... *I didn't want him to know yet, I wanted to sort all these things out for myself.*” P5.

Furthermore, she felt she had to ‘be strong’ for her sisters upon hearing the news.

“...yes let them come. ‘cause I need to sit them down and I need to just explain to them the situation, that I'm in and there's nothing to panic about. I've got breast cancer, I'm having the mastectomy done, I will still be alive ... it was a very sad moment....but I had to be stronger of the five you know, I had to tell them, each one nicely.” P5.

This illustrated the concern that women had for their families in sharing a breast cancer diagnosis. Concern for family in the face of breast cancer diagnosis appeared to overshadow personal fears.

In addition, women felt a concern for the care of their children whilst they were ill. Moreover there was a concern for the emotional impact of a breast cancer diagnosis on their children. One participant shared how she managed her two teenage daughters, “*I step by step prepared them.*” P7. While a mother of a two-year-old son attempted to maintain the bond with her son throughout her journey: “*We had lots of “mommy-Seany time. “ I'd explain to him what happened that um that mommy's breast was sick.*” P2.

Due to physical weakness and fatigue experienced as a result of the cancer related treatments, mothers felt challenged in their motherly role. One participant voiced her helplessness and feelings of guilt toward her 16 year old daughter.

“Oh, that was terrible because especially with the chemotherapy, I was just useless. I sort of felt guilty because I couldn't do anything for my daughter. If it wasn't because of my friends and colleagues, who were feeding me, er, and giving me all the support I needed, you know, so, I am glad now that I am finished with it so that I can sort of considerate to her because, I neglected her...Not that I wanted to but I couldn't because I really couldn't...help myself. I was tired all the time.” P1.

These findings illustrate the psychological and emotional distress that women diagnosed with breast cancer experience. Women carried not only the shock associated with cancer diagnosis but also the burden of their family's well-being while facing a life threatening disease (Manuel, Burwell, Crawford, Lawrence, Farmer, Hege, Phillips & Avis, 2007:86). A South African study revealed that daughters of cancer-diagnosed mothers associated the word ‘cancer’ with death and dying. This led to feelings of helplessness and emotional distress (Mosavel *et al.*, 2010:793). However, some

daughters in this study felt that cancer was curable if the treatment was adhered to (Mosavel *et al.*, 2010:794).

The researcher found that the participants developed coping strategies in order to cope psychologically with the breast cancer diagnosis, the surgery and treatment and family responsibilities. Towsley *et al.* (2007:96) pointed out that a person transitions into survivorship by coping and finding a new balance as they face the challenge of disease and treatment. Coping with cancer related to coping with various factors such as pain, fatigue, anger, changes in appearance, and challenges facing relationships with partners and family (Manuel *et al.*, 2007: 86). Moreover, Wu and McSweeney (2007:123) stated that individualized strategies aided patients who suffered from fatigue to gain a sense of control. These strategies helped ease some of their fatigue.

Coping strategies identified in the findings were Acceptance, Being positive and Information avoidance.

The interviewees who used *acceptance* in coping with their diagnosis were capable of moving forward in the face of their challenges (Jim *et al.*, 2006:757). They tended to develop ways of adjusting to breast cancer, mastectomy and treatments in order to cope with the challenges that had to be faced. As stated, they sort to find a method of coping in order to find a new balance (Towsley *et al.*, 2007:96).

The following excerpts illustrate some of the coping responses revealed in the findings. The following participant saw herself as a statistic and accepted the journey ahead of her.

“Um...look I am quite a pragmatic person and you know the statistics, so I just thought oh well that is my statistic within my group because you know they were the age in my book club. So K was first and then it was my turn. So, I was, ja, I was not devastated by it, this is a journey I’ve got to go down now, um, I have always had a very strong faith, so I knew I would be fine “ P4.

Another participant felt that if she didn’t accept her diagnosis she would have a difficult journey ahead, she explained,

“ I....as I said, like...I probably...because I accepted it immediately, I didn’t, um...I just took it...if you, if you gonna to let cancer...um take you over and you’re just going to sit there and mope and feel sorry for yourself and all that, then you’re gonna have a long road...and ...I mean of getting to terms with that and all, but the moment they said it, once I was finished crying, that moment the doctor said, I accepted it and I didn’t...I didn’t look back, I didn’t feel, oh, it’s a breast and it’s a part of me and all thatso....for me the sooner you accept it then the easier ...” P3.

In accepting the diagnosis the participant felt that she would cope and would be able to walk the road ahead of her.

Positivity was identified as a coping strategy that women chose to maintain a positive outlook in the face of their breast cancer diagnosis. This played a role in maintaining the family's emotional needs since they too were affected by the cancer diagnosis. Findings revealed that it was important to women, to cope within their circumstances. They felt that their families had to be protected from their emotional distress of the breast cancer diagnosis. They felt that if they themselves coped psychologically, the family would cope within the circumstances. One participant said: "...but to me it was important that I coped well in order that my family coped well, you know if I had fallen apart, then I think everything else falls apart." P4.

However, the researcher noted in her field notes (participant 4), that the participant withheld deeper issues during the interview. She mentioned that she had to cope in order for her family to cope while "*the negative is having the damn stuff.*" This alerted the researcher that the participant chose to be positive in her situation while she dreaded her diagnosis.

Manuel *et al.* (2007:92) stated that the best coping strategy for women experiencing fears and uncertainty for the future, was positive cognitive restructuring. In this study the participants felt the need to protect their families as they sensed concern in their families (Allen *et al.*, 2009:76). In addition Manuel *et al.* (2007: 90) noted that positive cognitive restructuring was seen as a coping strategy by 'looking for the silver-lining' in their adjustment to breast cancer.

Moreover, *Information avoidance* was noted as a coping strategy amongst the women interviewed in this study. The researcher found they preferred to distance themselves from the emotional and psychological distress associated with information that would potentially challenge their world. Some women felt that the shock associated with a breast cancer diagnosis was in itself challenging.

One participant felt overwhelmed by information regarding breast cancer, treatments and recommended lifestyle changes.

"...from time to time at certain stages and certain points that I know enough just get myself by and to deal with the next stage, so ja I chose not to be too informed...and often you get people who come visit you and they want to, you know overload you with too much information and I at some point just shut off." P7.

While another participant voiced her preference to experience her journey as it unfolded.

"What I've noticed about me, I didn't want someone to tell me about cancer, what are they experiencing something like that, I wanted to, to be for me to be a first time

experience. Because I just say to myself I don't want to say...yo...the chemo, I'm going to get sick and stuff like that ...ah...ah..." P6.

Miles *et al.* (2008:1878) state that patients focused on reducing feelings of fear versus trying to minimise their chances of being effected or dying from the threat. Cancer patients felt that little could be done in the face of the health threat that could not be controlled. The avoidance of cancer information assisted the patient in gaining control of their fear.

4.3.2 Theme 2: Physical experiences

This subtheme discusses the *psychological impact of changes in appearance*, following surgery and treatment for breast cancer.

The following quote revealed the emotional distress experienced by a woman who was not able to accept her scar following breast surgery.

"But as the time goes I think now, it started sinking in, you know, because, um, I couldn't look at my scar. I don't know why... I didn't, I didn't, something just, I just felt like not looking at it. Meanwhile people who were seeing me, they saying it's beautiful, it's beautiful. Ah, its looking good, but I didn't feel like, I don't know", "probably that's how I overcame now that fear of the scar like knowing that even if I went for a cosmetic surgery, I was still gonna have this scar you know." P1.

Another participant articulated the emotional stress experienced as a result of losing her hair. She felt that hair loss was almost worse than experiencing breast loss. She expressed, that she was *"almost becoming uglier by the day... you know you appear to be an alien."* P7. In contrast to the negative feelings regarding hair loss, another participant noted that her sons supported her. *"The boys...they loved me with my bald head."* P5.

These findings reveal the psychological distress associated with an altered appearance due to cancer and its treatments. Women had individual experiences in their adjustment.

Manuel, Burwell, Crawford, Lawrence, Farmer, Hege, Phillips & Avis (2007:86) stated that adjustment and quality of life were found to be associated with coping strategies after breast cancer diagnosis. Coping strategies varied according to the specific stressor. Women may use a variety of ways of coping with the different aspects of breast cancer. What is effective in dealing with body image changes may not be effective in dealing with emotional fears (Manuel *et al.*, 2007:93).

4.3.3 Theme 3: Social experiences

The sub-themes discussed under social experiences are, Making changes and the Cultural impact of breast cancer.

The sub-theme Making changes, relates to the changes that women made following mastectomy in order to adapt to their circumstances. Women experienced emotional distress when they were faced with an altered appearance and revealed a need to appear normal in society.

The following quote revealed the 'panic' experienced and the adjustments this participant made when she lost bodily hair.

"I was like busy wiping then when I like looked, I noticed that there's hair all over the toilet paper...Then I went to the mirror now, to look at my hair, yo.... under the hairpiece there is something happening...I say...aahh...then I noticed, I don't have eyelashes, I don't haveum. Nothing at all, under arms, nothing, nothing, nothing, it was clean , clean , clean, I say ok, I mustn't panic, I went to buy my wiggy, I buy all my, um, the eyebrow pencils, everything , then I just draw, nobody even noticed that. Nobody knows that I didn't have the hair all this time I was like visiting them with wigs."
P6.

Another participant voiced her need to appear "balanced" when appearing in society. She stressed the importance of being able to engage with her students and chose a bilateral mastectomy.

"I mean I, my biggest thing is that because I work with people all the time, you don't want (sigh) anything about the way you look to be a barrier between you and engaging with them, so for example...with the students." P4.

Manuel *et al.* (2007:92) revealed that women who had a positive outlook, engaged in physical activity and made changes were more able to cope with altered appearance, lifestyle and physical abilities.

The *Sub-theme, Cultural impact of breast cancer*, revealed the social implications of women diagnosed with breast cancer.

Interview findings revealed challenges in the Xhosa culture with regard to the lack of knowledge regarding breast cancer and treatments. As noted in the literature review, Xhosa speaking patients regarded cancer as a killer disease and a curse. Patients felt socially isolated (Lourens, 2013:109), since breast cancer is not talked about in the Xhosa community (Lourens, 2013:110).

A participant noted that the Xhosa culture faced fears regarding cancer diagnosis and surgery and held onto the belief that they needed to return to the grave as a whole person.

"...because as I am saying you know, cancer ...no one talks about it...I think because, they've got that thing of saying there is no cure", "...again people they don't want to remove because they rather...because they want to go to the grave fully, not with a part missing, so is the breast...you know." P1.

This participant believed that this could be a reason that women tended to not opt for mastectomy in the face of breast cancer. Her desire to plan a support group for women within her community was noted in the researcher's field notes.

Another participant voiced her concern for an acquaintance: "...she doesn't want to play with their grandchildren, because she's like afraid that she's going to infect them." P6.

This participant indicated that within the Xhosa culture there seemed to be a belief that breast cancer is infectious and can be transmitted to children.

In addition there seemed to be a lack of knowledge regarding mastectomy and reconstruction with prosthesis. One participant, who had prosthetic reconstruction, shared the following experience whilst washing with other women. Their response to her follows:

"...you say to us you don't have a breast what we are seeing that there is a breast...ye ye ye ye...why did you have to lie to us, and stuff like that. I say you know what, what you are doing is so rude, so rude, you were supposed to ask me to show you my breast.... They don't even understand what is that." P6.

These findings substantiate the need for African women and their families to be educated and informed regarding breast cancer, treatments and surgery.

The researchers' field notes, noted that participant 6, was very open about her experiences after diagnosis of breast cancer, and her family's reactions. She mentioned cultural points of fear of cancer in her community as well as cancer being contagious. She wished to educate Xhosa women.

4.3.4 Theme 4: Support needs in the transition Survivorship

The sub-themes discussed hereunder are Psychological support from family and friends, Physical support needs, Support needs of the affected family and Support groups.

Allen *et al.* (2009:76) stated that even though the completion of treatment was a milestone for some women, results showed that women faced a time of hardship, uncertainty and isolation. Reasons for emotional distress were related to the loss of medical monitoring and the vulnerability after treatment is completed. There was an increased sense of responsibility related to self-monitoring. Allen *et al.* (2009:72) stated that women who reported high levels of stress during the transition period tended to have a diminished long term adjustment in survivorship.

Interview findings revealed the *sub-theme, Psychological support from family and friends* as a support structure in the transition to survivorship.

Women following mastectomy, found their families to be the most supportive and the greatest support structure in their transition. One participant voiced her need for support. "*People to support*

me, especially my family, I just needed them next to me.” P6. While another participant found that the experience brought her family together: “It brought the family closer um...what else...because I think that’s the most important thing, just having your support around you.” P3.

Support was also received from friendships, neighbours and church communities. There seemed to be a need for friends who could be trusted and who would be prepared to walk the journey with their affected friend. A participant, who was single, articulated her appreciation for the support of her friend who accompanied her to treatments.

“Fortunately there was a friend of mine, who was so supportive to me, we went there together... so I needed support, I really needed support, and I was so grateful that my friend was there.” P1.

Moreover another participant shared that she found support within her friendship groups. In addition, a friend, who walked a similar journey, informed her of the road ahead. The participant expressed,

“I just felt held the whole through the whole thing and your friends are amazing... you know I’ve got a little book club and what was so helpful was having K who had been through exactly the same thing a year before.” P4.

The researcher in her field notes (P4) noted that it became clear that ‘personal support’ appeared to be the most meaningful in the journey of women following mastectomy within their journey to survivorship. This related to personal support from a friend, someone who can be trusted/ share experiences. However as noted, the participant did not mention her husband as a support when probed.

Illingworth, Forbat, Hubbard and Kearny (2010:25) noted that an individual’s illness experience is related to and situated within their interpersonal relationships. There was a joint ownership of cancer and treatments. A supportive environment was found within the family and companionship.

Furthermore the *sub theme, Physical support needs* pointed to the physical weakness and fatigue women experienced due to the effects of cancer and cancer related treatment.

A participant who suffered from depression shared of her need for support with household chores by saying, *“if people can just deal with that, I can create my own emotional wellbeing ...” P7.* While another participant articulated how she wanted to be supported, *“Just you can support me by giving me, allowing me to rest for so...so long afterwards, for so many hours, or you can support me by making me a meal.” P2.*

One participant expressed her gratitude for her neighbours support while she felt ill,

“my beautiful neighbour next door... she washed me and she creamed me every day ... And she would take my...she would strip my bed every day, every day and she

would take my bedding with her and my nighty and my panty and she would take it home with her and then tomorrow morning when she comes around, she brings that stuff all clean washed and ironed” P5.

In addition women had weakness in their arms on the operative side of the mastectomy. They also had to face the effects of chemotherapy and radiation, which affected their ability to cope with normal day-to-day activities. One participant shared:

“I’ve got a lady that comes in and help me...she still comes in and that, because of the cut I can’t like sweep, mop and stuff like that. Only now recently I’m starting to do that ... Ja, weakness, because they took out the, what’s it, the lymph nodes as well. Sometimes I just pick up something and it drops, so I’m not sure if that maybe was because of that.” P3.

Wang and Woodruff (2015:450) stated that Cancer Related Fatigue produced by cancer or its treatment, is a distressing and persistent symptom for both survivor and families. Women reported that when their fatigued bodies were no longer controlled by their will, they reported feeling lazy, unproductive and guilty. In addition to suffering from their illness and treatments they also suffered from the pressure of being unacceptable to their personal belief and value system as productive people (Wu & Mc Sweeney, 2007:123).

In addition, *sub-theme, Support needs of the affected family* was identified, as a support need. Breast cancer diagnosis had an impact on the family.

A participant, in seeing her family respond to her breast cancer diagnosis, realized that she had to ‘be strong’ in order for her family to cope.

“I just told myself you know what, I need to accept this and to be strong for my family because they are falling apart, the way I’m seeing them they’re falling....I just need to strong for this people now.” P6.

Another participant noticed that her family did not know how to cope with her situation in relation to her needs following mastectomy.

“I think a family in this situation actually feels helpless, they don’t know how to assist you and um. I think it’s quite important from someone who has had a mastectomy for you to be able to actually say to your family. This is how I would I like to be supported, I think it’s quite important for you to be able to say that to your family...this is how I would like to be supported. And without...you’re not sounding selfish. ” P2.

These findings revealed evidence that the family have needs in supporting their loved one who is facing breast cancer. Benzein *et al.* (2008:108) avers that health, including family health, embraces illness and disease. Adams, Boulton and Watson (2009:183) noted that partners or spouses of

breast cancer patients reported a need for information on causes and risk factors, chances of survival, impact of cancer on everyday life and alternative therapies. In addition, education on Cancer Related Fatigue (CRF) should be given to families in order to minimize the stress and anxiety associated with the condition (Wang & Woodruff, 2015:450).

In support of the above findings, on visiting a participant, the participant's sister voiced her appreciation for information regarding breast cancer that she received from her neighbour's experiences: "...because I think if it wasn't for her, then we wouldn't have been so prepared also, so you see..." Sister of P3.

The above excerpts illustrate the need of the family to be educated and supported in the journey of living with a relative suffering from breast cancer.

Finally the *sub-theme*, *Support groups* was discussed in the transition period to survivorship of women following mastectomy. Interview findings revealed that women preferred or experienced that most of their support came from families and friends.

However, some women formed friendships within their chemotherapy group. A participant shared the following:

"it's like a family thing ...because you meet everybody, same time, if you go today, three weeks later you get that same people ...you see...chemo... Yes, and you keep in touch... we make friends like that." P3.

Another participant found it difficult to attend a support group due to financial strains. She shared "*I would have loved to have attend a support group, if I was by the means to get to one, I don't have a car.*" P5.

Moreover, due to cancer related fatigue some women had no energy to seek out a support group. Their families provided the support they needed. De Nijs, Ros & Grijpdonck (2008:192) noted that CRF had serious effects on the daily life and quality of life of patients. This related to some women needing daily care and not being able to work. There was also a correlation between CFR and psychological distress such as anxiety, depression, difficulty in sleeping and a low degree of physical functioning.

One participant articulated that she felt too weak and depressed to attend a support group.

"...um, you know and she's encouraged me on two occasions to join them and I actually chose not to, and made up an excuse because I didn't, because it's like a rehashing of the same thing and they talk about it over and over again... but I'd rather be in a positive space with positive people from time to time than rehashing the same experience and all those dark experiences." P7.

This participant felt that she preferred to join a support group at a later stage when she was able to choose a group, which would influence her positively.

From these findings, the researcher concluded that woman walked their own journey after breast cancer diagnosis. Each woman had to manage her illness and cope in her own way.

Field notes: The researcher was aware of her inexperience in interviewing the participants on a personal and sensitive topic. On the first interview the researcher became aware of the need to guide the participant and to become aware of opportunities to probe for a deeper understanding of experiences. On interviewing participant 3, the researcher felt that the participant was nervous and the interview felt superficial, however, on transcription of the interview the participant's family greeted the researcher warmly. It was then that the participant removed her headscarf to show the researcher the progress of her hair growth. At that moment the researcher felt that she had the ability to establish good relationships with the participants in the study and that the research was worth it. As the research process continued, the researcher identified a need for women to share their experiences on a personal level. On interviewing participant 5 and 7, the participants thanked the researcher for the "therapy."

4.4 SUMMARY

In exploring the lived experiences of women following mastectomy the following support needs within the transition to survivorship were identified. *Psychological needs* referred to the emotional stress and shock women experienced on breast cancer diagnosis. Women had concerns and fears regarding surgery and treatments. There was also concern for the wellbeing of their families. Due to the individuality of each participants experience, each participant developed their own coping mechanism/style that helped them on their journey to recovery.

Physical needs were identified since the women experienced physical symptoms such fatigue, weakness due to treatments and surgery. Cancer and Cancer treatment Related Fatigue was shown to play a part in the well-being of women diagnosed with breast cancer. They felt too ill or weak to attend to their normal family duties or to attend a support group. In addition, they faced an altered appearance due to the effect of surgery and treatments and had a need to appear normal in society.

Social needs identified, included cultural challenges of women diagnosed with breast cancer and needs within the family structure. Culturally, it was identified that Xhosa-speaking women needed to be supported and educated in their own language. In addition, the researcher found that most families were involved in the care of their relative diagnosed with cancer. Families took on the stress related to breast cancer diagnosis and its treatments and had a need for information and emotional support.

Based on the philosophical underpinnings of the post positivist view of Husserl, the researcher gained data from the participants by using semi-structured interviews with open-ended questions during dialogue. In articulating their experiences, the researcher was able to explore the phenomenon related to the lived experiences following breast cancer diagnosis.

The researcher, on meeting with the participants for interviews, offered a small gift, a choice of soaps and chocolates to the participants thanking them for agreeing to contribute to this research. The choice each woman made, demonstrated to the researcher, the uniqueness of each individual that was reflected in what they selected. To the researcher, this highlighted and confirmed the initial assumption at the conception of this research that each woman experiences her journey following breast cancer in a personal way.

The following chapter will discuss the research and its findings, based on the aims and objectives of the study, which was to explore and describe the lived experiences of women following mastectomy.

CHAPTER 5: DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

The previous chapters contain a description of the rationale for this study and an in-depth literature review regarding the needs of women following mastectomy for breast cancer as they transition to survivorship. A description was also provided of the research methodology and data analysis for the purpose of this study.

This chapter contains a discussion of the findings of the study, conclusions drawn from the analysis and recommendations based on the findings. Future research suggestions are proposed.

5.2 DISCUSSION

The aim of the study was to interview women in the Cape Metropole in order to explore and describe what their lived experiences following mastectomy were as they transitioned to survivorship.

Psychological, physical and social support needs of women following mastectomy were identified. Support needs related to needs within the transition period to survivorship.

5.2.1 Psychological experiences of women following mastectomy.

As in the study by Remmers *et al.* (2010:12) the participants in this study revealed that they experienced psychological stress and shock after breast cancer diagnosis. There were fears of uncertainty. Stressors related to surgical treatment, altered self-perception and stress caused by their social environment. Schmid-Büchi *et al.* (2011:262) noted that women feared cancer spreading, had an uncertainty for the future, loss of control, experienced lack of energy, feelings of sadness, and depression. The women in this study expressed similar concerns and needed help in the post treatment period. Furthermore, they faced psychological distress related to the well-being of their families. This is substantiated by Boehmke and Dickerson (2006:1124) who found that women felt that their priority remained with their families and not themselves. The psychological stress of breast cancer diagnosis also led to extreme fatigue.

However, literature showed that in the midst of this life changing event some women revealed that having cancer enhanced their appreciation of life and their willingness to fulfil delayed dreams. Some of the participants articulated a sense of finding the “silver lining” and felt empowered by surviving the experience. A woman voiced that the experience had its purpose in opening her eyes. Some attempted to make positive changes in the face of breast cancer. This included new

health behaviours such as exercise, cessation of smoking, dietary changes, controlling stress and engaging in spiritual practices (Allen *et al.*, 2009:74). As in this study, Hamilton *et al.* (2007:315) noted that spirituality was seen as a coping strategy that aided women in survivorship.

The way that some participants perceived herself and her experience of the challenge, contributed to her journey. Each woman found her way of coping with the stressors she faced. Wu and Mc Sweeney (2007:123) notes that positive meaning could be derived from fatigue. This was used as a defence mechanism, which protected one participant from a psychological breakdown in facing uncertainty.

Furthermore, some women, in the midst of stress, had accepted their diagnosis while maintaining positivity in not allowing any negativity. Some participants, in line with the study by Manuel *et al.* (2007:92) first sort social support, secondly positive cognitive restructuring and thirdly, physical activity to cope with anxiety, depression and anger. Two participants in this study stated that maintaining a positive perspective seemed important to them and their families as substantiated by Boehmke and Dickerson (2006:1125). Positivity 'killed the cancer' and aided them psychologically in surviving the diagnosis and taking care of their children. In contrast some women felt that due to their experience, they would never return to their "normal" self (Allen *et al.*, 2009:75).

In contrast to information avoidance, information seeking was influenced by feelings of anxiety and fear as well as emotional variables like perceptions regarding treatment, self-efficacy and locus of control. Locus of control referred to the degree by which fate is governed externally versus control by oneself (Case, Andrews, Johnson & Allard, 2005:359). This perspective was articulated by a number of the participants. Interestingly, in one family, the researcher of this study, noted that families of patients, in contrast to the patients themselves, had high information needs (Schmid-Büchi *et al.*, 2011:264).

In contrast to the challenges that women faced, Mollica and Newman (2014:337) state that survivors often felt that they needed to serve others who are experiencing difficult times. This explains the participants who expressed a desire to develop a support group in her community.

This study revealed that breast cancer diagnosis was life changing and caused fear and emotional distress in the lives of women affected by it. They adapted to their individual journey by using coping strategies and found meaning in order to find a new balance in the challenges they faced. Schmid-Büchi *et al.* (2013:27) notes that the breast cancer challenge was an individual experience for each patient. However, in this study it appeared that not all the patients needed help in the adjustment process.

5.2.2 Physical experiences of women following mastectomy.

The researcher identified that physical needs related to another that of taking care of the tasks that the patient could not attend to. Physical weakness occurred due to cancer, cancer related treatments and surgery. Surgery resulted in weakness of the arm on the operative side. Women felt unable to maintain their role of mother, wife and partner. This is substantiated by Van der Steeg *et al.* (2008:1228-9) who found that women following mastectomy, faced challenges on general health perceptions, physical functioning, low energy, fatigue and role limitations.

Moreover, physical symptoms due to chemotherapy included muscle pain, joint pain and peripheral neuropathy. Even though it is noted in the literature that exercise is the most effective intervention in combatting Cancer Related Fatigue, the participants in this study felt unable to engage in physical activity (Boehmke & Dickerson, 2006:1126). During chemotherapy treatments women face a dilemma. In the face of debilitating symptoms, women feared the cessation of chemotherapy cycles since they felt that they were active in fighting the cancer (Boehmke & Dickerson, 2006:1126). This was not expressed by the participants in this study. In fact, they were accepting of the treatment regimen.

Schmid-Büchi *et al.* (2013:27) recognised that supportive care needs of breast cancer patients are predominantly in physical daily living, health care information and psychological needs. This was articulated by most of the participants in this study.

In addition, the participants in this study were emotionally and physically challenged as they faced an altered body appearance due to surgery and treatments. Remmers *et al.* (2010:13) stated that altered self-perception was experienced when women were confronted with their altered appearance for the first time such as a deformed breast or absence of a breast. The participants expressed this as an appalling experience. This resulted in insecurity and grief. They felt that their femininity was threatened. Literature reveals that distress may also be linked to a negative self-perception, leading to uncertainty, which negatively influenced their self-esteem and belonging needs (Schmid-Büchi *et al.*, 2013:27).

Findings in this study, revealed that some women were devastated by hair loss while another found it interesting. Some women bought a wig, while some preferred a headscarf. Boehmke and Dickerson (2005:385) noted that women expecting hair loss were still traumatised by it. However, one participant stated that she didn't wear a wig since baldness was her badge of honour. This confirmed the individuality of the journey faced by each woman.

Cancer and cancer treatment related symptoms were associated with a higher need in daily activities, psychological and social needs, such as assistance with household chores and provision of meals, as found by Schmid-Büchi *et al.* (2011:264).

Even though the participant's reactions, symptoms and experiences were individual, as in the study by Boehmke and Dickerson (2005:388), the symptoms were commonly reported as stressful by them.

The researcher concluded that women faced physical weakness as a result of mastectomy and its treatments and relied on family support during survivorship. Families are in essence part of the journey.

5.2.3 Social experiences of women following mastectomy.

The social needs of the participants in this study, mirror the findings of Koczwara and Ward (2015:342) who commented on the phenomenon of breast cancer. Their study explored the concept 'cancer survivor' socially, politically and culturally. The cultural prominence of the 'breast cancer experience' was examined. The author argued that the 'breast cancer experience' provided a lens for people diagnosed with cancers. This may be empowering or may negatively amplify the sense of being different. There appeared to be issues of 'pink envy' and 'hierarchies of suffering' where breast cancer is perceived as more fortunate than other cancers. In society, the polarisation of breast cancer and associated 'survivorship' may be due to media and experiences shared by celebrities. It was noted that 'other' cancer survivors perceived themselves to be in the shadow of a breast cancer survivor. However, in this study, none of the participants specifically made reference to being worse or better off than other cancer sufferers.

Breast cancer as a phenomenon is not just a reflection of biological and social standing, but also of societal selection. This implies that breast cancer is a more sanitised and palatable version of cancer that is more acceptable to society. This phenomenon is perceived by society as reassuring and communicates that cancer can be overcome, treatment can be successful and longevity can be assured. However, in this study, it was evident that the participants did not feel privileged. There was a lack of knowledge by the participants as to their treatment plans and their families did not have enough knowledge to support them safely. Despite one publication that stated that 'survivorship' implied heroism, bravery and unique social standing that has given many cancer sufferers a voice, it was not evident in this study sample. The authors do however, argue that this has narrowed the scope of what is heard, such as the day to day struggles of cancer sufferers (Koczwara & Ward, 2015:343).

Furthermore, the 'survivorship' of women diagnosed with breast cancer is influenced by the individual's understanding and perceptions of cancer. In this study, culture, community, family events and beliefs influenced this as substantiated in the study by Barnato, Llewellyn-Thomas, Ellen, Peters, Siminoff, Collins and Barry (2007:627). They found that patient's perceptions of cancer were influenced by cultural beliefs, attitudes and values, which could be overwhelmed by 'physician talk' during a consultation. There is a need to respect the patient's autonomy which could ensure better communication and may lessen harm to the patient. This perception was

articulated by one participant who was grateful to a friend for accompanying her to her appointments.

Women preferred social support within their interpersonal relationships (Schmid-Büchi *et al.*, 2013:25). Schmid-Büchi *et al.* (2011: 263) noted that due to cancer and cancer treatment related symptoms women felt physically and socially impaired. Social impairment related to leisure, work and daily activities. Hodgkinson, Butow, Hunt, Pendlebury, Hobbs and Wain (2007:520) stated that the women who were in relationships were better able to identify needs and access supportive care services. However, Hodgkinson *et al.* (2007:519) noted that family/partner of survivors had information needs themselves and a need to talk to others who have had similar experiences. Schmid-Büchi *et al.* (2011:263) added that the burden relatives carried was almost as high as that of the patient. This is true of the data gleaned from the interviews in this study both for women with partners and one single woman.

A study by Ali, Fergus, Wright, Pritchard, Kiss and Warner (2014:52) revealed that ninety-two percent of the daughters informed their mothers of their breast cancer diagnosis. Fifty-five percent of the women reported that their mothers experienced shock, disbelief, fear, sadness and devastation. However, forty-five percent of daughters said that in the face of sadness their mothers remained strong, comforting and supportive. These findings are similar to the feelings one sister of one participant articulated in this study. Daughters reported that the breast cancer experience had a positive impact on their mother-daughter relationship where relationships were valued and brought closer. Fifty-three percent of daughters stated that the support received from their mothers was unconditional and overwhelming. This was articulated by one participant in this study. Mothers supported their daughters with food preparation, shopping and household chores. Thirty-six percent of daughters described that their mothers understood their experience in that they themselves had experienced breast cancer diagnosis. However, some daughters had expected more support from their mothers (Ali *et al.*, 2014: 53).

Ali *et al.* (2014:54) noted that thirty-nine percent of the women in the study felt that their mothers did not have adequate social support, where seventy-one percent reported that healthcare professionals could assist their mothers. Daughters believed their mothers had needs for information regarding investigations, treatment, prognosis and the unique needs of breast cancer patients. In addition women believed that support groups would assist their mothers and in doing so would lighten the burden carried by mothers and aid them in supporting their daughters. This aspect of support was not explored in the current study since children were not interviewed but is a recommendation for future research.

5.3 LIMITATIONS OF THE STUDY

The limitations of the study relates to a small sample, although literature is not consensual on the optimal or minimal number of participants needed in a phenomenological study to improve the trustworthiness of the findings.

Moreover, the phenomenon of the transition of a breast cancer patient to survivor is extensive and this study in the opinion of the researcher, only achieved a fairly superficial grasp of the challenges women face.

Finally, this is the first study of this nature conducted by the researcher where the methodology required a new set of academic skills, namely, interviewing individuals on a personal and sensitive topic. Despite receiving training on interview techniques from the university, the researcher acknowledges that her lack of experience led to self-consciousness which may have influenced her ability to effectively engage with the participants.

5.4 CONCLUSIONS

A descriptive phenomenological study was completed to explore the lived experiences of women following mastectomy with the aim of determining support needs in their transition to survivorship. Survivorship relates to the time when women stepped out from medical care into 'their lives' (Allen *et al.*, 2009:71). After recruiting women residing in the Cape Metropole, interviews were conducted in order to identify the support needs of women following mastectomy.

The researcher bracket her own assumptions related to the research in order to explore the phenomenon.

The researcher concluded that since families were identified as the primary care giver once the patient had left the care of health care givers, families, most effectively met the support needs of women following mastectomy in survivorship. Due to the increased burden and emotional impact on the family, the researcher understood that the family had a need for support and information regarding breast cancer diagnosis, treatments and surgery. By providing support, families would be more equipped to assist their loved one in her journey, which would influence support in survivorship.

In addition, in the researcher's field notes written after interviewing participant 4 it is noted that:

"It is becoming clear to the researcher that 'personal support' appears to be the most meaningful in the journey of women following mastectomy, within their transition to survivorship. This relates to personal support from a friend, someone who can be trusted in order to share experiences and faith".

For the value of support groups, it appears that women following mastectomy are less likely to attend support groups due to physical weakness experienced as a side effects of cancer and

cancer related treatments. Support groups would be considered at a later stage. The following excerpt was noted in the researcher's field notes.

"... an invitation to a support group - declined. Due to the participants hardships she felt like she didn't want to stay in the negativity. She sees a support group for later in the journey".

5.5 RECOMMENDATIONS

5.5.1 Recommendation 1

The researcher recommends that further research should be focused on the needs of the family since they appear to be the most important source of support for a woman following mastectomy. Family members need to be supported with information on how they can assist their affected family member.

5.5.2 Recommendation 2

The researcher recommends education of Xhosa-speaking women with breast cancer. This should be done, as suggested in literature, by a Xhosa-speaking woman, so that there is an understanding of the disease and its treatments.

5.5.3 Future research

- A survey or qualitative study on the support needs of families of cancer sufferers is, according to the findings of this study, urgently required.
- A study exploring the need for education amongst Xhosa-speaking women regarding breast cancer, surgery and prosthesis, could provide empirical evidence that may influence a change in public health care and education.
- The support needs of women living in rural areas is a topic primary health care nurses working in rural areas could research, of which the findings could bring illumination to the needs of survivors of mastectomy for breast cancer.

5.6 DISSEMINATION

The researcher will present her findings at conferences such as the Annual General Meeting of Reach for Recovery scheduled for June 2016. A publication in a peer reviewed journal is planned.

5.7 CONCLUSION

As stated by Wu and Mc Sweeney (2007:123), in order to understand the experiences of women with regards to fatigue, lessons learned, meaning discovered and the individual coping strategies they developed in the face of cancer, one has to understand the world in which they live. Husserl's phenomenological philosophy was applied in this study by the researcher who remained objective and where her own ideas, bias or judgments were set aside, or bracketed.

Findings revealed the individuality of each woman's experience as she faces breast cancer and experiences the effects of mastectomy and treatment. Women have adapted in their own individual way in the transition to survivorship to cope with their diagnosis, surgery, treatments and their personal lives. Support needs are based on the individual's psychological, physical and social needs. Women have shown to be concerned more for their family than themselves in the light of their situation. There was a need for family support for those taking on the role of primary care givers of their loved one in survivorship. A need for breast cancer education and information in a language understood by the cancer sufferer was highlighted.

The research question posed for this study was answered by the small sample of participants who were representative of the women residing in the Cape Metropole. It contributes to the body of nursing knowledge about the needs of women following mastectomy.

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APPENDICES

Appendix 1: Ethical approval from Stellenbosch University



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Ethics Letter

27-May-2015

Ethics Reference #: S14/11/266

Clinical Trial Reference #:

Title: Experiences of women following mastectomy in the Cape Metropole.

Dear Miss Nicole STECHER,

Your letter dated 2 May 2015 refers.

Your response to the stipulations requested by HREC has been accepted.

You may proceed with your research project.

If you have any queries or need further assistance, please contact the HREC Office 0219399657.

Sincerely,

REC Coordinator
Franklin Weber

Health Research Ethics Committee 1

Appendix 2: Participant information leaflet and declaration of consent by participant and investigator

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:

Experiences of women following mastectomy in the Cape Metropole

REFERENCE NUMBER: S14/11/266

PRINCIPAL INVESTIGATOR: Nicole Stecher

ADDRESS:

CONTACT NUMBER:

You are invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

- The study aims to explore the experiences of women following a mastectomy. This will increase the awareness of healthcare workers with regards to the needs of women following a mastectomy.
- Interviews will be conducted for about 45-60 minutes. The setting will be of your choice.
- Interviews will be electronically recorded and will be kept confidential. Anonymity will be ensured. Your name will not be mentioned.
- No risks are identified. In the event of emotional sensitivity/stress, you can be referred to a support structure if you choose.

- The information from interviews will count as data that may be verified by the facilitator.

Why have you been invited to participate?

- You have been invited for the study because you can share your experiences following a mastectomy.

What will your responsibilities be?

- To participate in interviews and to share your experience following a mastectomy.

Will you benefit from taking part in this research?

- *Sharing your experiences will help nurses and other families in understanding what it is like to have a mastectomy. This information could also help to prepare women who have to go for a mastectomy.*
- *The only risk of this study could be that you feel too vulnerable or sensitive to share your experience. We can refer you to a counsellor if you choose.*

If you do not agree to take part, what alternatives do you have?

- If you choose to not participate, you have the right to stop.

Who will have access to your medical records?

- All information given to me will be confidentially kept and stored in a safe place. Your name will not be mentioned in the research. The facilitator, who assists in the study, will see the information but is obliged to maintain confidentiality.

What will happen in the unlikely event of some form of injury occurring as a direct result of your taking part in this research study?

- There are no injuries identified in this study. If you feel too emotional to continue with interviews, you can be referred to a counsellor if you choose.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study.

Is there anything else that you should know or do?

- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study nurse.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled **“Experiences of South African women following mastectomy.”**

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 2015.

.....
Signature of participant

.....
Signature of witness

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) on (*date*) 2015.

Signature of investigator

Signature of witness

Declaration by interpreter

I (*name*) declare that:

- I assisted the investigator (*name*) to explain the information in this document to (*name of participant*) using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) on (*date*)

.....
Signature of interpreter

.....
Signature of witness

Appendix 3: Interview guide

Interview Guide: Proposed questioning route based on objectives and Reach for Recovery guidance

Introductory question: -

- Which events led you to discover that you have breast cancer?

Probing questions: -

- Did you have support once you were at home?
- Did you feel supported by healthcare workers whilst receiving treatments?
- Did you feel that your questions were answered and that you were prepared for treatment?
- Would you say culture played a part in your journey of breast cancer?
- How did you experience the effects of surgery and treatments?
- How did your experience your family's reaction to the diagnosis?
- What was the most helpful to you in your journey after treatment?

Ending questions: -

- What would you say were your positives and negatives in your experience?
- What would you recommend to women who are newly diagnosed with breast cancer

Closure: Is there anything that we haven't discussed that you feel is important?

Appendix 4: Extract of transcribed interview

An extract from Participant 7:

Ja, one thing I also wanted to mention to you...was, immediately when I was diagnosed, in having...because then you have to go for all the tests, and you sit in doctors room and sit in waiting rooms and so...and life is just going by. Everything is just completely normal on the outside and that actually um, that affected me quite badly, you know having been, where your life changes just within that one day or

And nobody else knows it

Or in that one phone call

and they are carrying on...

You're sitting, you're sitting and you actually think thoughts, and I think, now I feel bad, um I almost feel like it was wicked thoughts and begrudging, whatever, and you look at somebody, like I remember particularly sitting at C. The day I had to go and do my pre admission and I saw somebody walk past with a cool drink and a packet of chips and I just thought to myself, you're walking here with a packet of chips and a cool drink like nothing is happening, do you actually know how my life has.... it's quite honestly those are the thoughts that went through my mind and then I sort of checked myself and I thought you know this person has absolutely, has done absolutely nothing wrong, I was that person a few days ago um and just because my life has now changed, I'm thinking all these, all these begrudging thoughts, um but those are the thoughts, because you almost want to tell the whole world, you know do you realise what's happened to me um do you realise...you know what's going on in my body or what I'm going to be going through in the next few days, um, you know so those are almost your desperate thoughts...

You are crying out for help,

Yes

Somebody please recognise me, and please see me and please help me and show me what I must do...

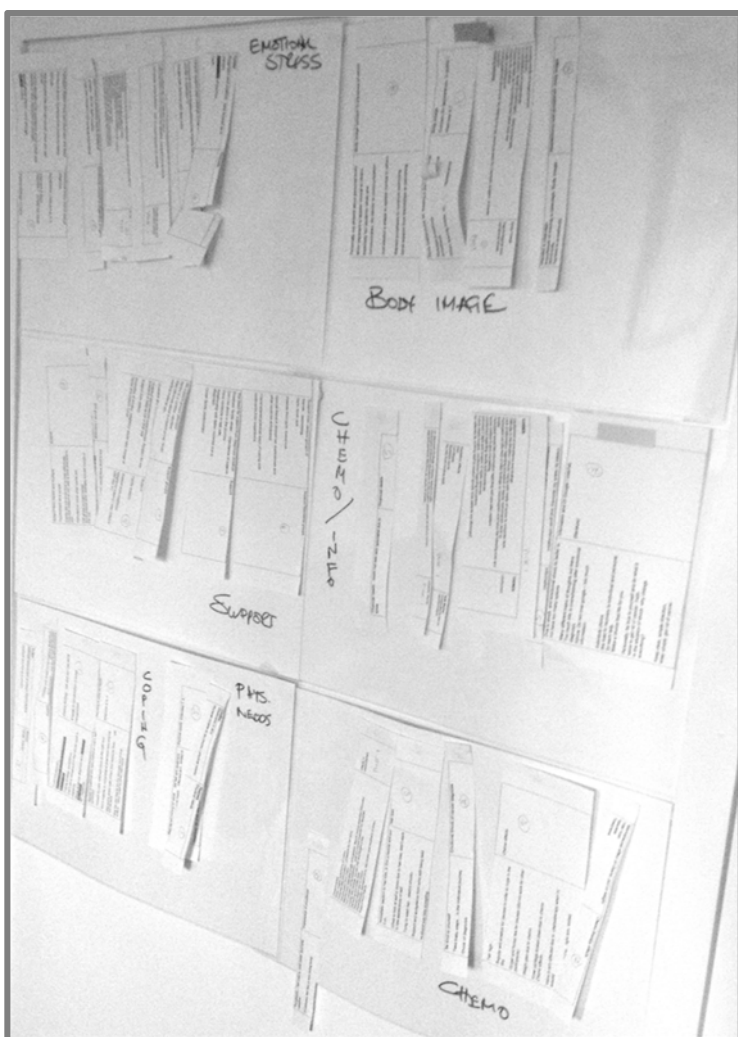
And, and you know, um, can you almost help me or hold my hand, through this experience, you know these feelings um because you are also not sure, because the thought of...although I had been to hospital on previous occasions and had ops and

so on, um you always just hear about that one op that went wrong or the anaesthetic that um didn't quite work out well or those are the thoughts, when you go into hospital you do sort of think you know and you do say your prayers. And you try to think all the positive and good the thoughts, but there are those thoughts at the back of your mind. Um and um, ja just people they carrying with their normal lives and people and you know even the staff, or um, the, the nursing staff they are very...try to be compassionate and so on, and you think to yourself you know but you are trying to be sympathetic and compassionate, but you actually don't really...its not you going through all of this and experiencing this.

It's me I have to do it...

Yes, I am feeling the actual physical pain, those are the types of thoughts um, that I experienced...um

Appendix 5: Data analysis: Developing themes from codes.



Appendix 6: Plagiarism report.

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