EXPERIENCES OF PATIENTS WHO HAD UNDERGONE MASTECTOMY AT MANKWENG HOSPITAL IN LIMPOPO PROVINCE, SOUTH AFRICA.

By

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DECLARATION

I, Desmond Mnisi, declare that the dissertation “**Experiences of patients who had undergone mastectomy at Mastectomy Hospital in Limpopo Province South Africa** “hereby submitted to the University of Limpopo, for the degree Masters of Nursing Science has not previously been submitted for a degree at this or any other university; that it is my work in design and execution, and that all reference materials contained herein have been duly acknowledged.

Mnisi D Date: 01 April 2021

DEDICATION

I dedicate this research report affectionately to the following:

All the research participants that took part in this study and all the women who are suffering from breast cancer in Limpopo Province.

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First and foremost, I want to thank the almighty God for the wisdom bestowed upon me, the strength He provide to me and my supervisors during difficult times which slowed my progress.

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ABSTRACT

Background: Mastectomy is one of the treatments for breast cancer. It causes a change in the appearance of the breast thus causing a major effect on women’s self-image and a decreased sense of femininity that can lead to anxiety and depression to such an extent that they avoid visiting public places. The study explored and described experiences of women who had undergone mastectomy at Mankweng Hospital, Limpopo Province, South Africa.

Study design: This study used a phenomenological approach to perform a qualitative, exploratory, descriptive, and contextual research. Using a non-probability purposive sample of about 15 women who had undergone mastectomy in Mankweng hospital. Data were gathered through semi-structured interviews. The semi-structured interviews' audio recordings were transcribed verbatim. Seven steps procedure for data analysis using Colaizzi method was used to interpret the data.

Results: The most challenging experience by women who had undergone mastectomy defined as a feeling of being disabled, anxious, relieved, acceptance, and financial constraints.

Conclusion: Strategies to address the challenges faced by women who had undergone mastectomy has been developed to assist them with coping mechanism post mastectomy and living a normal life.

Key concepts: Breast Cancer, Mastectomy, Women

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LIST OF ABBREVIATIONS

BPM:	Bilateral Prophylactic Mastectomy
CANSA:	Cancer Association of South Africa
CDC:	Centre for Disease Control and Prevention
DoH:	Department of Health
LMIC:	Low and Middle Incoming Countries
SA:	South Africa
TREC:	Turfloop Research Ethical Committee
WHO:	World Health Organisation

DEFINITION OF CONCEPTS

- Experiences

Experiences is the feeling of emotions and sensations as opposed to thinking; involvement in what is happening rather than abstract reflection on an event (Farlex Medical Dictionary, 2012). In this study experiences means the psychological and physical impact on women post mastectomy.

- Mastectomy

Mastectomy is the surgical removal of the whole breast (Martin & Mcferran, 2008). In this study mastectomy means the removal of breast through undergoing an operation at Mankweng hospital.

- Woman

An adult female human being (Dictionary Oxford English, 2002). In this study, woman shall refer to an adult female who had undergone mastectomy procedures.

CHAPTER 1

OVERVIEW OF THE STUDY

1.1 INTRODUCTION AND BACKGROUND

Breast cancer is the second most commonly diagnosed cancer worldwide (WHO, 2015). According to World Health Organization report, there were about 519 000 women who die from breast cancer annually around the world and more new cases are found, which is estimated to be one million women who develop breast cancer each year all over the world (WHO, 2013). Since 2008, the incidence of breast cancer grew by more than 20% while, mortality increased by 14%. Breast cancer is the number two cancer amongst all females. It has been recorded that 1 in every 33 women in South Africa will develop breast cancer in their lifetime (Herbst, 2013).

Mastectomy is a common surgical treatment modality for breast cancer in which partial or full affected breast is removed to prevent further spread of cancer (Jetha, Gul & Lalani, 2017). Even if mastectomy is one of the treatments for breast cancer, it causes a change in the appearance of the breast thus causing a major effect on women's self-image and a decreased sense of femininity that can lead to anxiety and depression to such an extent that they avoid visiting public places (Jetha *et al.*, 2017). Koçan and Gürsoy (2016) found that mastectomy may negatively affect a woman's body image and her self-image. Women reported that they felt frightened, bad, strange, and different when they first saw their surgical site post mastectomy. Some women also indicated that their first look at the surgical incision shocked them and caused mixed emotional reactions (Koçan & Gürsoy, 2016). Drageset, Lindstrøm, Giske and Underlid (2011) state that mastectomy is necessary to regain health, but they also note that loss of the breast after mastectomy might result in conflicting or negative emotions.

Notman and Madelson (2013) found that in the United States of America (USA), sexuality was one of the most sensitive issues post mastectomy. They found that women felt unattractive, unfeminine and undesirable after breast surgery.

In extreme cases, women post mastectomy were unable to undress before their partners or even look at themselves in the mirror. Some women view mastectomy as a punishment for forbidden sexual fantasies or practices thereby further becoming sexually crippled (Notman & Madelson, 2013).

Arroyo and Lopez (2011) found that in Spain women who have had a mastectomy described it as an attack on their body image. They got worried about their aesthetic features and this made them no longer feeling beautiful. Arroyo and Lopez (2011) further state that these women post mastectomy tried to hide the loss of their breasts, having to deal with filling a bra or prosthesis since they were afraid others might discover their physical absence and also they see any glance as an attack on a zealously guarded privacy. This led to a fall in their self-esteem that drove the woman not to like herself or even to reject herself, leading her to an attitude of introversion, inward looking, shyness, insecurity, confinement, and/or social inhibition, which did not exist before mastectomy (Arroyo & Lopez, 2011).

Odigie, Tanaka, Yusufu, Gomna, Odigie, Dawotola and Margaritoni (2010) found that women in Northern Nigeria experienced a decrease in sexual activity which was not caused by a decrease in their own sexual arousal, but by the surgical removal of the breast which lessened their spouses' interest in sexual activity. Odigie *et al*. (2010) further suggest that these women and their spouses need to be given more information about the long-term side effects of breast cancer and its treatment. It is further indicated that while the minority of the participants experienced an increase in sexual activity, some demonstrated that there were other variables such as age, length of marriage, or religion involved in the change in sexual activity six months' post mastectomy (Odigie *et al*., 2010).

According to Manganiello, Hoga, Reberte, Miranda and Rocha (2011) women's sexuality post mastectomy was significantly more affected when these women had a lower educational level, older partners and had not done breast reconstruction. Kruger and Apffelstaedt (2007) state that the burden of breast cancer is increasing in Africa and this is further supported by WHO (2013), which stated that breast cancer is the leading cause of cancer deaths in the less developed countries around the world.

According to Austin and Armer (2011), breast cancer is the most prominent form of cancer in women in South Africa. It has been recorded that 1 in every 29 women in the country has been diagnosed with breast cancer. Austin and Armer (2011) further indicate that it is of great concern that much of the literature on breast cancer overlooks women's lived experiences regarding their diagnoses. They further indicate that there is a lack of research on the experiences of black South African women who have been diagnosed with breast cancer (Austin & Armer, 2011).

Austin and Armer (2011) further argue that it is vital to research these experiences in order to inform health initiatives and programmes concerning diseases of the breast. CANSA (2009) also states that there are many discrepancies in healthcare policies on a national as well as on a provincial level and that South Africa does not have an adequate healthcare programme in place for breast cancer patients. Therefore, little is known about the experiences of women post mastectomy in Limpopo province. This study therefore aims at determining the experiences of women who had undergone mastectomy at one tertiary Mankweng Hospital.

1.2 PROBLEM STATEMENT

The researcher was an employee at one tertiary hospital in Limpopo province. According to clinical observations by the researcher, one of the tertiary hospital admitted ninety-five (95) breast cancer patients from 2015 to 2016 at the surgical clinic. From the 95 breast cancer patients admitted, only eighty-five (85) was done mastectomy. The researcher found that mastectomy operations are done on 8 to 12 people per week and plus minus 100 per year dating from 2016 (DoH, 2016). All the women who received a mastectomy were from all 28 referring hospitals in Limpopo province. In South Africa, CANSA reported that the prevalence of breast cancer in 2012 was 22.68 % in black females, 41.07% in Asian females, 27.76% in coloured females and 10.06 % in white females. All the cases with breast cancer end up receiving a mastectomy if other treatment failed to cure.

The researcher observed that these women who had undergone mastectomy seem not to accept nor cope, (Some cry alone, some just keep quiet at all times which may be a sign of stress), all the observed during nursing rounds with the patients post mastectomy at one of the tertiary hospital hence it led to the research topic.

1.3 RESEARCH QUESTION

The following research question guided the study:

What are the experiences of women who had undergone mastectomy at a tertiary hospital in the Limpopo province, South Africa?

1.4 PURPOSE OF THE STUDY

The purpose of the study is to determine the experiences of women who had undergone mastectomy at a tertiary hospital in the Limpopo province, South Africa.

1. 5 OBJECTIVES OF THE STUDY

The objectives of this study are to:

- Explore the experiences of women who had undergone mastectomy at Mankweng hospital in the Limpopo province, SA.
- Describe the experiences of women who had undergone mastectomy at Mankweng hospital in the Limpopo province, SA.
- To recommend measures that may assist women who had undergone mastectomy at Mankweng hospital I the Limpopo province, SA.

1.6 THEORETICAL FRAMEWORK: ROY’S ADAPTATION MODEL

The research uses Roy’s theory of adaptation as a conceptual framework to analyse the experiences of women who had undergone mastectomy. Roy's theory defines adaptation as the process by which an individual or group makes conscious choices to cope with his or her situation (Sherman, 2013).

1.6.1 Four major concepts

1.6.1.1 Person

Roy defines a person as a recipient of nursing care and should be viewed as a holistic adaptive system (George, 1999). He further views a person as “an adaptive system with cognator and regulator subsystems acting to maintain adaptation in four adaptive modes” (Roy, 2011). Roy conceptualises a person in a holistic perspective. Individual aspects of parts act together to form a unified human being. The individual is also viewed as a living system that is in constant interaction with the environment. The individual is also conceptualised as having four modes of adaptation namely, physiologic needs, self-concept, role function and interdependence.

The four adaptive modes are explained further as follows:

- Physiological Mode: The individual adapts according to his/her physiological needs
- Self-concept Mode: The individual's self-concept is determined by his/her interaction with others. The physical self has the components of body sensation and body image. The personal self has the components of self-consistency, self-ideal and moral-ethical- spiritual self. Body sensation is how the person experiences the physical self and body image is how the person views the physical self.
- Role Function Mode: This mode relates to the performance of duties based on given positions within society
- Interdependence Mode: The interdependence mode identifies patterns of human values, affection, love and affirmation

In this study, a person will be the woman who had undergone mastectomy and who will undergo the four adaptive modes after the stimuli from the environment.

1.6.1.2 Environment

Roy (2011) defines environment as all conditions, circumstances, and influences surrounding and affecting the development and behaviour of persons and groups. The individuals are in constant interaction with a changing environment that requires the individual to adapt.

1.6.1.3 Health

Roy defines health in terms of a continuum from death to the highest level of wellness. Health and illness are viewed as inevitable dimensions of the individual's life.

1.6.1.4 Nursing

The goal of nursing is to promote adaptive responses in relation to the four adaptive modes. The goal of nursing is to promote the person's adaptation in his physiologic needs, his self-concept, his role function and his relation of interdependence during health and illness. According to Roy (2011), to the nurse acts as an external regulatory force to modify stimuli affecting adaptation

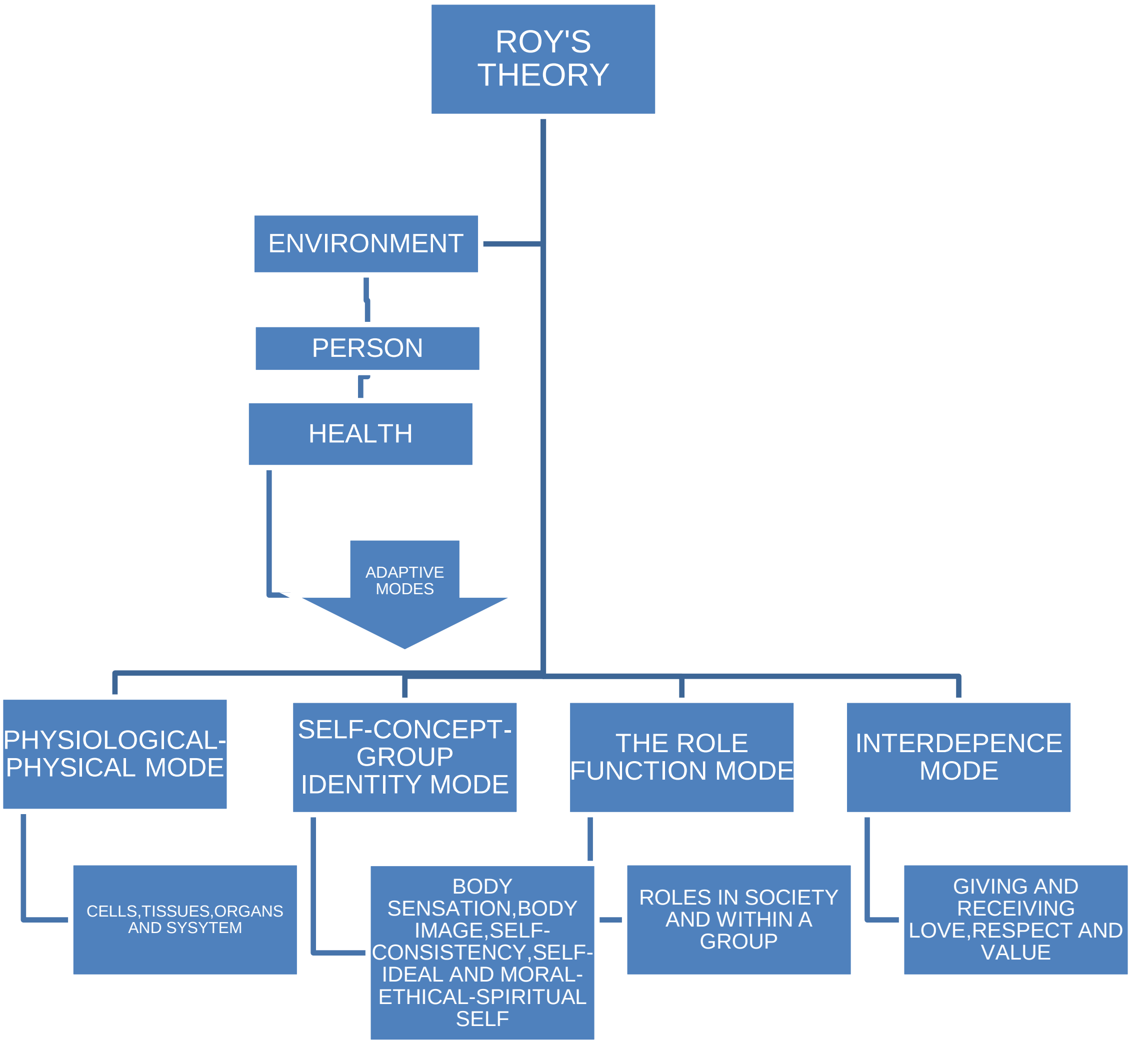

Figure 1.1: The Roy Adaptation Model

1.7 SUMMARY OF THE RESEARCH METHODS

A qualitative research method and an exploratory, descriptive and phenomenological research design are used to describe the experiences of women who had undergone mastectomy. The descriptive research design enables the researcher to describe in-depth experiences of women who had undergone mastectomy in a tertiary hospital. Purposive sampling is used to sample 15 participants. In-depth interviews were conducted to collect data until data saturation was reached.

The Colaizzi method was used to analyse data. Ethical considerations of informed consent, confidentiality and anonymity were observed. Measures to ensure trustworthiness include credibility, transferability, dependability and confirmability. Details of the research methodology are described in Chapter 3

1.8 SIGNIFICANCE OF THE STUDY

After determining the experiences of women who had undergone mastectomy at Mankweng hospital in the Limpopo Province:

Findings are presented to Mankweng hospital surgeons performing mastectomy procedures, hospital management and Limpopo department of Health. The results of this study may assist the Department of Health Limpopo to improve a quality of life for women’s post mastectomy by investing nor putting more effort into new guidelines for early detection of breast lumps and developing support groups and policy guidelines. This should provide awareness to all women in Limpopo province to be alert about early changes in their breasts thus reducing the spread of cancer with early treatment or intervention.

1.9 OUTLINE OF THE STUDY

Chapter 1: Overview of the study

Chapter 2: Literature review

Chapter 3: Research Methodology

Chapter 4: Results and discussion of the findings

Chapter 5: Summary, limitations, measures, recommendations and conclusion

1.10 CONCLUSION

This chapter focused on the introduction and background of the study, the problem statement, purpose and objectives of the study, the theoretical framework and a summary of the research methods. Furthermore, the anticipated significance of the study has been discussed as well. The next chapter focuses on the literature that supports the background of the study, and contrast to the study findings.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

Chapter dealt with the introduction and background of the study, research purpose and objectives as well as the study problem. The current chapter discuss the literature that relates to the study problem and it will be an integrated literature review. The literature has been extracted from various databases from both national and international sources. The aim of the chapter is to validate, contrast and support the study background, and findings. Mache and McEvoy (2016) define literature review as "a written document that presents a logically argued case founded on a comprehensive understanding of the current state of knowledge about a topic of a study". This case establishes a convincing thesis to answer the study's question. Blaxter and Hughes (2010) "then defines literature review as a 'systematic, explicit, and reproducible method of identifying, evaluating and synthesizing the existing body of competed and recorded work produced by researchers and scholars.'" According to Fink (2019), literature review surveys books, scholarly articles, and any other sources relevant to a particular issue, area of research, or theory, and by so doing, provides a description, summary, and critical evaluation of these works in relation to the research problem being investigated. Literature reviews are designed to provide an overview of the sources that have explored while researching a particular topic and to demonstrate to readers how the research fits within a larger field of study (Fink, 2019).

Snyder (2019) describes literature review as an excellent way of synthesising research findings to show evidence on a meta-level and to uncover areas in which more research is needed, which is a critical component of creating theoretical frameworks and building conceptual models. A Literature review is done because it is important for all research disciplines and all research projects because it can be the best methodological tool to provide answers, an overview of a certain issues or research problem, to create research agendas, identify gaps in research, or simply to discuss a particular matter and lastly, to evaluate the state of knowledge on a particular topic (Snyder, 2019).

Integrated literature review was used to search the literature. An extensive search of literature was conducted from 2009 March to 2020 using four electronic databases: EBSCOhost, Science direct, World cat, and Google scholar with the help of the library information specialist. The search terms for the literature used were: ‘‘Feelings post mastectomy, acceptance post mastectomy, support post mastectomy, experiences post mastectomy, breast cancer patients post mastectomy, psychological and physical impact post mastectomy’’. Articles were included if they explored experiences, challenges and support of women after mastectomy both qualitative and quantitative studies. Articles published before 2009 were excluded.

This literature review is intended to provide the researcher with information regarding women who had undergone mastectomy worldwide, in Africa as a continent, South Africa as the researcher’s country of birth and lastly Limpopo province where the researcher resides. Unfortunately no prevalence of mastectomy alone was found, each and every articles spoke of breast cancer and not mastectomy alone including the statistics from South Africa. Do they receive enough support at home by their beloved partners, relatives and friends?

2.2 PREVALENCE OF MASTECTOMY

Breast cancer is the second most common cancer worldwide. In 2012, the estimated number of new cases was 1.67 million (25% of all cancers). In Western Europe, there are 96 per 100 000 women with breast cancer. Breast cancer has a greater incidence (27 747), a greater prevalence over 5 years, and a greater mortality rate (6 213 deaths during 2014) than other cancers. The prevalence of breast cancer is increasing due to increased life expectancy and advanced diagnostic techniques for cancer (Ferlay, Soerjomataram, Dikshit, Eser, Mathers, Rebelo & Bray, 2015). Espina, McKenzie and Dos-Santos-Silva (2017) report that women in Africa currently have one of the lowest incidence rates of breast cancer worldwide yet it was disproportionately affecting African women in the prime of their lives, a growing aging population alone, that is, assuming incidence rates will remain constant can lead to an estimated 119 918 new cases in 2030, a near doubling in the number of cases over 20 years.

They state that the increase will be even more marked because incidence rates were likely to rise due to the adoption by African women to more westernised lifestyle profiles such as reproductive patterns which are characterised by late age at first full-term pregnancy, lower parity, reduced lifetime, breastfeeding duration, and increases in postmenopausal weight (Espina, McKenzie & Dos-Santos-Silva, 2017). During 2009–2011, 602 women were diagnosed with invasive breast cancer at Chris Hani Baragwanath Academic Hospital (Cubasch, Dickens, Joffe, Duarte, Murugan, Chih & Neugut, 2018). This disease represents a considerable public health burden in South Africa (Herbst, 2016). Data from the South African National Cancer Registry reports an increased incidence of breast cancer for women in 2011 of 6 849 per 100 000 per year, compared to 6 125 and 5 280 per 100 000 per year in 2010 and 2000, respectively (Herbst, 2016; National Health Laboratory Service, 2011).

When breaking down the statistics, the incidence to 6,849 represents 21.46% of all cancers in females, with a cumulative lifetime incidence risk (0-74 years) of 3.51% and a lifetime risk of 1 in 29 females developing breast cancer (National Health Laboratory Service, 2011) cited in Kramer, Ramjith and Shamleyb (2019).

2.3 EXPERIENCES OF WOMEN WHO HAD UNDERGONE MASTECTOMY

2.3.1 Psychological impact post mastectomy.

According to a study by Stecher, Cohen and Myburgh (2019), it is reported that women who had had a mastectomy experienced shame. This was as a result of losing their breast which to them was a symbol of beauty, sensuality and femininity thus playing a huge role in their self-image and value in society. Participants found hair loss devastating while others accepted it. Sun, Ang, Ang and Lopez (2018) report that women in their study also had psychological problems, like feeling that they lost their identity as women and felt like half women; they felt like their femininity had been lost and their gender status or womanhood changed to genderless. Mastectomy did have a negative impact which affected the women’s psychological well-being post mastectomy according to Koçan and Gürsoy (2016).

Participants interviewed felt incomplete without their breast, are no longer able to fulfil their responsibilities thus leading to depression. They felt uglier while some cried while explaining such an experience. Being without a breast brought shame as they felt deformed thus altering their self-esteem; they felt depressed, not feeling like a woman anymore thus diminishing their feelings of femininity and their self-confidence (Koçan & Gürsoy, 2016). Some patients reported to have suffered a psychosocial impact after breast reconstruction as a result of the mastectomy; mastectomy led to breast reconstruction which further affected their psychological well-being. They reported to have cared for their breast very well which was satisfying their partners as it was part of sexual arousal (Schmidt, Wetzel, Lange, Heine & Ortmann, 2017).

Findings from the study by Shrestha (2012) reveal that women expressed the fear of death, emotional impact of the loss of breast disfigurement, loss of femininity, fear of recurrence of disease, and concern about their family because of breast cancer and mastectomy. Breast cancer and mastectomy have impact on women's psychosocial state.

They develop stress due to loss of a body part, loss of femininity, fear of recurrence of disease, fear of cost and prolong treatment protocol. McClelland, Holland and Griggs (2015) report that affected body images as a result of mastectomy was the cause of emotional distress to post mastectomy women. This in turn elevated stress thus disrupting the normal social functioning of their everyday life. It is also stated that these women who had undergone mastectomy are under a level of stress due to lack of social support and support from the partner and family. The stress is further elevated by delayed breast reconstruction which could boost their self-esteem (McClelland, Holland & Griggs, 2015). The aforementioned are supported by Teo, Reece, Christie, Guindani, Markey, Heinberg and Fingeret (2016) who state that breast reconstruction post mastectomy is intended to facilitate psychosocial adjustment, including body image enhancement and quality of life. Research by Shrestha (2012) reveals that mastectomy caused psychological impact on women with breast cancer, which included fear of death, disfigurement, fear of recurrence of the disease, physical pain and discomfort, inconvenience in working and social communication, less sexual acts and low spirit. Research by Shrestha (2012) work reveals that mastectomy caused psychological impact on women with breast cancer, which includes fear of death, disfigurement, fear of recurrence of the disease, physical pain and discomfort, inconvenience in working and social communication, less sexual activity and low spirit.

Sawin (2012) reports that women who had breast cancer did not receive enough support which left them psychologically affected. Some husbands were never there when needed by these women who had had breast cancer which left them an unexpected hurdle to add to the stress of breast cancer; they felt like the breast cancer diagnosis made their partners angry. These women felt like their husbands lost respect for them and they were no longer worthy to their partners.

2.3.2 Physical impact post mastectomy

As a result of changes in their body image, post mastectomy women felt unable to attract men by showing off their cleavage, as it was no longer there. It even made them wear clothes that were big enough to hide their prosthesis or lack of real breasts (Arroyo & Lopez, 2011). According to Koçan and Gürsoy (2016), patients reported that they felt frightened, bad, strange, and different when they first saw their surgical site post mastectomy. Some women also indicated that their first look at the surgical incision shocked them and caused mixed emotional reactions.

As a result of mastectomy, some were afraid of the surgical side whereas some felt bad, different and weird to be without a breast or both. Due to the impact of mastectomy, some opted not to look in the mirror anymore because of the missing breast which they were not used to living without (Koçan & Gürsoy, 2016).

Sun, Ang, Ang and Lopez (2018) report that women who had undergone mastectomy felt as if it were an undesirable sight to look at their mutilated chest; their chest was seen as flattened and scarred thus disfiguring their physical body and the missing breast disrupted the sense of symmetry and harmony to their body structure. They went on to state that some women who lost their breast felt like they are aliens to their body and deemed themselves ugly, imperfect and abnormal from other women which had an impact on their psychological well-being (Sun, Ang, Ang & Lopez, 2018). Sawin (2012) reports that post mastectomy, some women were left with a flat chest due to bilateral mastectomy which took away their usual physical attraction of having two breasts.

Koçan and Gürsoy (2016) found that mastectomy may negatively affect a woman’s body image and her self-image. Women reported that they felt frightened, bad, strange, and different when they first saw their surgical site post mastectomy. Some women also indicated that their first look at the surgical incision shocked them and caused mixed emotional reactions (Koçan & Gürsoy, 2016).

Arroyo and Lopez (2011) found that the loss of the breast through mastectomy was experienced by women around Spain as an attack to the body image worrying about aesthetic features from that moment, which provokes the feeling that the women felt no longer beautiful.

Arroyo and Lopez (2011) further state that these women post mastectomy tried to hide the loss of their breasts, having to deal with filling a bra or prosthesis since they were afraid others may discover their physical absence and also they see any glance as an attack on a zealously guarded privacy. After the surgery, many women described what they saw as “wretched, horrible, scary, ugly, crooked, collapsed shape”.

However, the most commonly used description of their appearance was that they looked incomplete and half because they did not have two breasts (Koçan & Gürsoy, 2016). Mushtaq and Naz (2017) state that a breast is considered to be a unique part of a body which adds to the beauty of women. Removal of a breast is thought to be a reduction in body image. Their study found that women after mastectomy suffered from chronic distress due to the loss of an attractive organ of their body. They develop fears regarding their beauty, femininity, recurrence and fear of death in the near future.

According to the study conducted in the United States of America by Fobair, Stewart, Chang, D'onofrio, Banks and Bloom (2006), body image and sexual problems were experienced by a substantial proportion of women in the early months after diagnosis. Half of the 546 women experienced two or more body image problems some of the time (33%), or at least one problem most of the time (17%). Fobair *et al.* (2006) state that greater body image problems were associated with mastectomy amongst sexual active women and possible reconstruction, hair loss from chemotherapy, concerns with weight gain or loss, poorer mental health, lower self-esteem, and the partner's difficulty in understanding their feelings. Among the 360 sexually active women, half (52%) reported having a little problem in two or more areas of sexual functioning (24%), or a definite or serious problem in at least one area (28%) (Fobair *et al.,* 2006).

For the younger woman the mastectomy scar on her body was perceived as an ‘attack’ on her femininity and the potential long term effects of the breast cancer treatment had life changing ramifications (Coyne & Borbasi, 2009).Mushtaq and Naz (2017) state that a breast is considered to be a unique part of a body which adds to the beauty of women. Removal of the breast is thought to be a reduction in body image. Their study found that women who have undergone a mastectomy suffered from chronic distress due to the loss of an attractive organ of their body. They develop fears regarding their beauty, femininity, recurrence and fear of death in near future.

2.3.3 Sexual dysfunction post mastectomy

According to the study conducted by Fouladi, Pourfarzi, Dolattorkpour, Alimohammadi and Mehrara (2016) in Iran, women who had had a mastectomy experienced a change in sexual behaviour. They reported a decrease in libido thus decreasing the normal sexual intercourse as before the mastectomy; some even went to the point of avoiding having sex with their husbands which can lead to sexual dissatisfaction. This is further supported by Soderberg (2013) who stated that sexual dissatisfaction created family problems to some families. As such, the aforementioned sexual dissatisfaction caused distancing from spouses and separation from marital relationship. Harirchi, Montazeri, Bidokhti, Mamishi and Kazem Zendehdel (2012) support it by stating similar results where breast cancer patients experienced deterioration in sexual functioning over time following mastectomy treatment.

Due to radical mastectomy, young women reported having female orgasmic disorder which was then followed by early menopause dyspareunia (Kedde, Van de Wiel, Schultz & Wijsen, 2013). Leila, Nada, Kais and Jawaher’s (2016) study reports a decrease in the frequency of sexual intercourse as a result of vaginal dryness and dyspareunia. The decrease was caused by chemotherapy treatment which is done post mastectomy. The interviewed women in Tunisia felt less sexually attractive and had a decrease in libido. Maniselvi, Antony, Ponmuthu and Chellappa (2016) also reported that patients were not satisfied with their sexual life post mastectomy and also due to the adjuvant treatment.

Arroyo and Lopez (2011) report that post mastectomy patients felt less attractive and valueless towards their partners thus developing low self-esteem, all due to the loss of their breasts. Their relationship started to deteriorate due to lack of sexual desire post mastectomy as they felt ugly when looking at themselves without their breasts. Some women even went to the extent of not showing their chests to their partners and had sex wearing a bra or a shirt to hide the operation site.

Those without partners had anxiety and many questions regarding disclosing their situation of being without breasts. They did not know how their new partners will feel nor react when he sees their naked body (Arroyo & Lopez, 2011). Rowland and Metcalfe (2014) indicate that the physical disfigurement caused by mastectomy resulted in men feeling less sexually attracted to their women who had had a mastectomy. It then resulted in avoiding to touch their partner intimately nor engage in sexual intercourse. Though some did have a desire to have sex, they just did not want to cause more physical damage to the breast scar wounds. Rowland and Metcalfe (2014) further state that mastectomy had a severe impact on marital relationships and was seen as strenuous. Sexual problems encountered as a result of poor body image acted as a catalyst for couples to separate. According to Cheng, Sit and Cheng (2017), participants in their study expressed passive acceptance in coping with their altered sexuality and had to reduce the frequency of sexual activity nor stopped having sexual intercourse with their husbands. Due to post mastectomy, sexual intercourse was no longer the same; some women had to cover their chest when having sexual intercourse which was described as taking away the passion for sex that was good before mastectomy and they no longer felt sexy (Sawin, 2012).

Their reasons for stopping or reducing sexual intercourse was because they deemed it less important than health, they then avoided it to preserve health according to their understanding (Cheng, Sit & Cheng, 2017). As a result of feeling genderless, women who had undergone mastectomy suffered with their spouses regarding intimacy. They started to have insecurities; their sexual life started to deteriorate because their partners only kissed them and skipped the breasts side. As time goes on, sexual desire was lost and abstinence kicked in and sexual life was no longer part of the relationship and thus leaving these women affected (Sun, Ang, Ang & Lopez, 2018). Notman and Madelson (2013) found that sexuality was one of the most sensitive issues post mastectomy in their research study in the United States of America. They found that women felt unattractive, unfeminine and undesirable after breast surgery. In extreme cases, women post mastectomy were unable to undress before their partners or even look in the mirror. Some women experienced mastectomy as a punishment for forbidden sexual fantasies or practices thereby further becoming sexually crippled (Notman & Madelson, 2013).

Northern Nigerian women indicated that there was a decrease in sexual activity which was not caused by a decrease in their own sexual arousal, but by the surgical removal of the breast which lessened their spouses' interest in sexual activity. This suggests that these women and their spouses need to be given more information about the long-term side effects of breast cancer and its treatment (Odigie, Tanaka, Yusufu, Gomna, Odigie, Dawotola & Margaritoni, 2010). Women's sexuality post mastectomy was significantly more affected when they have a lower educational level, older partners and have not done breast reconstruction (Manganiello, Hoga, Reberte, Miranda & Rocha, 2011). Gahm, Wickman and Brandberg (2010) state that the ability to feel sexual sensations in the breasts was totally lost and impaired post Bilateral Prophylactic Mastectomy (BPM) in their study. The breasts were reported to have held greater importance in sexuality before BPM for the majority of patients. Those patients reported that sexual importance of the breasts and sexual enjoyment changed in a negative way after the bilateral prophylactic mastectomy. High sexual importance of the breasts before BPM was related with reduced enjoyment of sex and with a negative change in the breast sexual importance after the BPM (Gahm *et al.,* 2010).

Reduced intimacy was expressed with a sense of loss and sadness by many men and was experienced by most couples regardless of their age or the length of time that the couple had been together. Several men indicated that the physical disfigurement caused by the mastectomy resulted in feeling less sexually attracted to their partner and as a consequence they did not want to touch their partner intimately or engage in sexual intercourse (Rowland & Metcalfe, 2014).

Findings from the study by Shrestha (2012) reveals that women expressed the fear of death, emotional impact of the loss of breast disfigurement, loss of femininity, fear of recurrence of disease, and concern about their family because of breast cancer and mastectomy.

Sun, Ang, Ang and Lopez (2018) reported that women in their study also had psychological problems, like feeling that they lost their identity as women and felt like half women; they felt like their femininity had been lost and their gender status or womanhood changed to genderless. Mastectomy did have a negative impact which affected the women’s psychological well-being post mastectomy according to Koçan & Gürsoy (2016).

Participants interviewed felt incomplete without their breast, can no longer fulfil their responsibilities thus leading to depression. They felt uglier while some cried while explaining such experience. Being without a breast brought shame as they felt deformed thus altering their self-esteem; they felt depressed, not feeling like a woman anymore thus diminishing their feeling s of femininity and self-confidence (Koçan & Gürsoy, 2016).

The aforementioned is supported by Teo, Reece, Christie, Guindani, Markey, Heinberg and Fingeret (2016) who state that breast reconstruction post mastectomy is intended to facilitate psychosocial emotional adjustment, including body image enhancement and quality of life.

2.3.4 Social impact post mastectomy

Some patients reported to have suffered a psychosocial impact after breast reconstruction as a result of the mastectomy which led to breast reconstruction which further affected their psychological well-being. They reported to have cared for their breast very well which was satisfying their partners as it was part of sexual arousal (Schmidt, Wetzel, Lange, Heine & Ortmann, 2017). Findings from the study by Shrestha (2012) reveal that women expressed the fear of death, emotional impact of the loss of breast disfigurement, loss of femininity, fear of recurrence of the disease, and concern about their family because of breast cancer and the mastectomy. Breast cancer and mastectomy have an impact on women’s psychosocial state. They develop stress due to loss of body part, loss of femininity, fear of recurrence of disease, fear of cost and prolonged treatment protocol. McClelland, Holland and Griggs (2015) report that affected body images as a result of mastectomy was the cause of emotional distress to women post mastectomy. This in turn elevated stress thus disrupting the normal social functioning of their everyday life. It is also stated that these women who underwent mastectomy are under a level of stress due to lack of social support and support from the partner and family. The stress is further elevated by delayed breast reconstruction which could boost their self-esteem (McClelland, Holland & Griggs, 2015).

2.3.5 Emotional impact post mastectomy

Sawin (2012) reports that women who had breast cancer did not receive enough emotional support which left them psychologically and emotionally affected. Some husbands were never there when needed by these women who had breast cancer which left them with an unexpected hurdle to add to the stress of breast cancer. They felt like the breast cancer diagnosis made their partners angry. These women felt like their husbands lost respect for them and they were no longer worthy to their partners. Drageset, Lindstrøm, Giske and Underlid (2011) state that mastectomy is necessary to regain health, but they also note that loss of the breast after mastectomy might result in conflicting or negative emotions.

2.4 COPING STRATEGIES FOR PATIENT WHO HAVE UNDERGONE MASTECTOMY.

2.4.1 Support Group

It is said that mastectomy can affect a woman's identity thus having a serious effect on their personal, emotional, family and social life, self-esteem and bodily image (Adorna, Morari-Cassol & Ferraz, 2015). According to Ursavaş & Karayurt (2017), a cancer support group is seen as a significant means that meets the social support requirements of cancer patients. The support group is supposed to comprise of family members, friends and health care teams. The group is regarded well enough if it has from 6 to 20 participants, meetings lasting for an hour or an hour plus. The place for support group get together should be easily accessible and known by everyone in the group (Ursavaş & Karayurt, 2017). That can be supported by the quote, "what people know and believe to be true about the world is constructed or created and reinforced and supported as people interact with one another over time in specific social settings" (Dyer & Coreil 2017).

In their results, Ursavaş & Karayurt (2017) conclude that a support group enabled women with breast cancer to cope better as a result of understanding that they were not alone and thus the support group helps them to support each other. According to Bigatti, Wagner, Lydon-Lam, Steiner and Miller (2010), both social hope and social support have been identified as important factors that contribute to positive psychological outcomes between patients and spouses in the context of cancer recovery. Samarco (2009) reported that younger women's with breast cancer received high social support whereas the elderly ones did not. The reason was said to be due to a reduction in social networks while ageing. The aforementioned statement is supported by Hasson-Ohayon, Goldzweig, Dorfman and Uziely (2014) as they report that younger women were relying on social support to cope with cancer while older women relied on their hope as an inner source to cope with depression brought into their lives by breast cancer.

Lohne, Miaskowki and Rustoen (2012) state that spouses are affected differently after their partners' diagnoses of cancer. They reported that younger spouses which were caregivers to their partners with cancer reported a high level of emotional strain as compared to elderly caregivers. Adorna, Morari-Cassol and Ferraz (2015) report that being in a support group allowed women who had undergone mastectomy not to feel lonely, they no longer felt isolated as they met other people who had undergone mastectomy and shared stories in terms of their breast cancer experience. These women further got a chance to talk with others who had had a mastectomy or have a breast cancer experience.

As a result of sharing or exchanging experiences, these women developed a bond for each other thus improving their self-esteem regarding quality of life while living with breast cancer nor post mastectomy. Some who were not free to talk about breast cancer with their family members, partners or friends about mastectomy felt free to share during support group sessions (Adorna, Morari-Cassol & Ferraz, 2015). Many women perceived being around women who had been on cancer treatment for cancer survivors as important during support groups. They reported that the support they receive from having experienced women regarding cancer was more than qualitatively different than those given by family or friends. It is reported that cancer survivors who were peer leaders in those support groups came with important information from their shared experiences (Dyer & Coreil, 2017).

Another good thing reported by Dye and Coreil (2017) about a support group was that, it brought fellowship and sisterhood thus allowing participants to bond with each other. Women who were still undergoing treatment reportedly sometimes had negative emotions; negative emotions came with further illness and those who were breast cancer survivors strived their best to discourage such. Cancer survivors in a support group instilled hope and courage in those suffering from breast cancer (Dyer & Coreil, 2017). According to Rubenstein (2015), socially supportive environments offered an opportunity to consider the relationship between emotion and information behaviour during support group sessions. The researcher reported that these people were not necessarily becoming friends but they showed affection towards each other as they interacted in those support group meetings. Participants were reported to have closed gaps on each other; they interchanged and shared lived experiences on how they survived or coped with breast cancer experiences (Rubenstein, 2015).

Participants were reported to offer each other much needed emotional support or information in a more comfortable environment. The support they offered each other was something that family and friends could not provide in such a comfortable atmosphere (Rubenstein, 2012). Eaton, Bright, Zeng and Hayley (2017) report that cancer recurrence was mentioned as a concern by these women of whom some were cancer survivors with post breast cancer treatment. They stated that breast cancer patients found comfort to talk about their disease during clinics when meeting with other breast cancer patients and being in a group. Some women reported that it was better to talk with other women with breast cancer or post breast cancer treatment during support groups and clinics, than sharing with people from the community because they viewed it as a private topic. Because they were not aware of how a neighbour, for an example, can react when they share, they kept it to close family and friends (Eaton, Bright, Zeng & Hayley, 2017).

Eaton, Bright, Zeng and Hayley (2017) add that without support groups post mastectomy or breast cancer treatment, these women are deprived from receiving emotional support from other patients who understand breast cancer better. They are deprived from speaking about it anymore in a comfortable environment. As a result of not meeting other patients post breast cancer treatment, if there is no support group or clinics for follow up, all of the women who were interviewed stated that they received limited or no information about long-term breast health or the risk of recurrence at the post breast cancer treatment (Eaton, Bright, Zeng & Hayley, 2017). Banning, Hassan, Faisal and Hafeez (2010) report that women received support from peers to assist them to cope with their emotional and personal well-being. Other women preferred to visit homeopaths for treatment and never informed their immediate family members. This was because some reported negative responses regarding their breast cancer diagnosis. Therefore, without a support group, these women received emotional support and reassurances from the hospital staff that they would recover (Banning, Hassan, Faisal & Hafeez, 2010).

Setoyama, Yamazaki and Nakayama (2011) report that the support group made women who had had a mastectomy due to breast cancer to realise a similar experience. It made them not to feel it is a unique problem. Women who had more years with breast cancer and undergone a mastectomy came to support groups just to be cheerleaders, to motivate and inspire those suffering thus instilling hope and allaying anxiety. Closer relationships then developed amongst them over time as they always faced each other.

2.5 CONCLUSION

The chapter provided a literature review that support, compare and contrast the study’s background. The literature was obtained from various databases, both national and international. The next chapter provides a detailed discussion about the research methodology that is applied to address the research problem.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

Chapter 2 dealt with literature review on how women who had undergone mastectomy felt post mastectomy. This chapter deals with the methodology used during the research in order to determine the experiences of women who had undergone mastectomy at a tertiary hospital in the Limpopo province and how it is applied following the literature discussed in chapter 2. These include a series of steps and procedures followed in the research study to meet the objectives of the study. Research methodology is the path through which researchers systematically conduct research, formulate problems and objectives, and then present their results from the data obtained during the study period (Indu & Vidhukumar, 2019). In this study a qualitative research approach is used in order to enable the researcher to explore and describe the experiences of the women who had undergone mastectomy. The researcher will also develop strategies that may assist women who had undergone mastectomy at tertiary hospital to cope .Burns and Grove (2007) state that qualitative research is a way to gain insights through discovering meanings and by understanding the whole through exploring the depth, richness and complexity of the phenomenon under study. A qualitative research approach is used to explore and describe the experiences of women who had undergone mastectomy at Mankweng hospital in Limpopo Province.

According to Teherani, Martimianakis, Stenfors-Hayes, Wadhwa and Varpio (2015), qualitative research is the systematic inquiry into social phenomena in natural settings. Under these phenomena, the researcher outlines how these women who had undergone mastectomy at Mankweng experience aspects of their lives, how they behave at home post mastectomy and during follow ups at the hospital, and lastly how they feel post mastectomy in terms of their physical appearance, their self-esteem, sexuality and how they value themselves in the society.

3.2 RESEARCH DESIGN

Research design is the overall plan for addressing a research question, including the specifications for enhancing the study's integrity (Polit & Beck, 2010). Explorative, descriptive, and contextual research designs are used.

3.2.1 The explorative design

The explorative design is used in this study to gain insight into and an understanding of the problem under study in which the researcher will ask questions and allow the participants to respond (Henning, Van Rensburg & Smit, 2004).

An exploratory design is conducted about a research problem when there are few or no earlier studies to refer to or rely upon to predict an outcome. Exploratory designs are often used to establish an understanding of how best to proceed in studying an issue (Indu & Vidhukumar, 2019). Under this study, it is to explore and describe the experiences of women who had undergone mastectomy at Mankweng hospital in the Limpopo province.

According to Van Wyk (2012), exploratory design is the most useful research design for those projects that addresses a subject about which little is known or there is ignorance about the subject. The main aim of exploratory research is to identify the boundaries of the environment in which the problems, opportunities or situations of interest are likely to reside and to identify the salient factors or variables that might be found there and be of relevance to the research (Van Wyk, 2012).

3.2.2 A descriptive design

A descriptive design describes situations and events. The purpose of descriptive is to provide a picture of a situation as it naturally happens (Burns & Grove, 2007). A descriptive design will assist the researcher with obtaining complete and accurate information on the experiences of women that had undergone a mastectomy. Nassaji (2015) states that the goal of descriptive research design is to describe a phenomenon and its characteristics and, it is thus more concerned with what happened rather than how or why something has happened. Descriptive research design therefore, attempts to study language learning and teaching in their naturally occurring settings without any intervention or manipulation of variables (Nassaji, 2015). Siedlecki (2020) further supports the aforementioned by stating that, descriptive design describes individuals, events, or conditions by studying them as they are in nature and the researcher is not supposed to manipulate any of the variables.

Therefore, descriptive research must provide an accurate, clear and valid representation of the factors or variables that are relevant to the research question (Van Wyk, 2012). A descriptive design is used to assist the researcher in obtaining complete and accurate information on the experiences of women that had had a mastectomy in Limpopo Province.

3.2.3 The contextual design

Contextual research strategy intends to describe and understand events within the concrete, natural context in which they occur (Babbie, 2013). Qualitative research data collection requires the researcher's self-immersion into the participants' worldview (Bitsch, 2005). The contextual interest of the researcher is to understand the experiences of women who had undergone mastectomy.

Contextual research strategy intends to describe and understand events within the concrete, natural context in which they occur (Babbie, 2013). Beyer (2010) defines contextual design as a structured, well-defined user-centred design process that provides methods to collect data about users in the field, interpret and consolidate that data in a structured way, use the data to create and prototype product and service concepts, and iteratively test and refine those concepts with users.

3.3 STUDY SETTING

Study settings is defined as the physical location and conditions in which data collections takes place (Brink, Van der Walt & Van Rensburg, 2012). The study was conducted at two selected tertiary hospitals in the Limpopo province.

The chosen tertiary hospital number 1 performs mastectomy operations for all women with breast cancer in the Limpopo Province and also provide some few follow up and review, whereas the other tertiary institution number 2 offers a variety of therapy options for all cancer patients, including those who have had mastectomy. In tertiary hospital number 2, most of the follow-ups and reviews after mastectomy or for all cancer patients are performed. Post-mastectomy, women continue to get chemotherapy and radiation at tertiary hospital number two.

The selected hospitals are situated in the Capricon district of the Limpopo province. Limpopo Province has five districts namely: Capricorn, Vhembe, Sekhukhune, Waterberg and Mopani.

Tertiary hospital number one is situated in Capricorn district near the University of Limpopo (Turfloop campus) while Tertiary hospital number two is situated at the centre of Polokwane City as illustrated on the map below. Patients across the five districts have access to both these two tertiary hospitals as all hospitals refer patients to them. They use planned patient transport on a daily basis to come to the two hospitals. Since patients that were interviewed came from different hospitals, the researcher only highlighted the two tertiary hospitals on the map below for Limpopo Province.

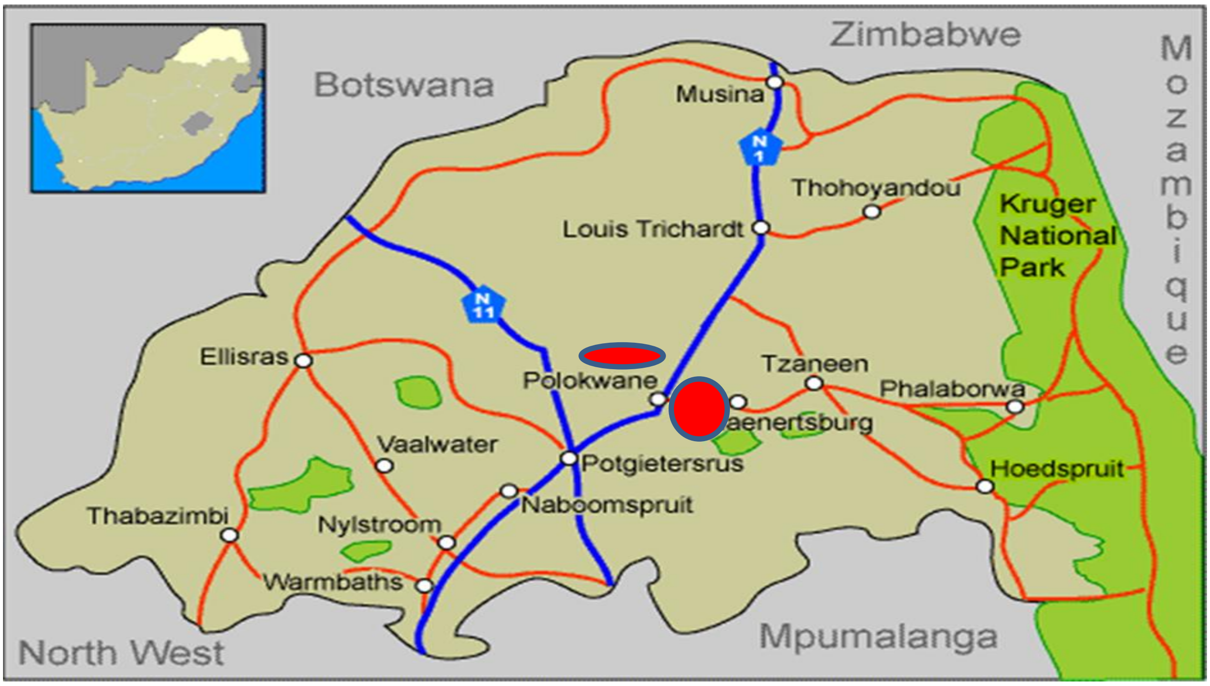

Figure 3.1: Limpopo map indicating the two tertiary hospitals used in the study for data.

3.4 POPULATION

According to Polit and Beck (2008), population is all the individuals with common defining characteristics. According to Polit and Beck (2014), population is defined as all the individuals with common defining characteristics where the researcher intends to study. The population of this study were 15 women who had undergone mastectomy at the selected tertiary hospitals in Limpopo province.

3.5 SAMPLING

Sampling refers to the process of selecting a portion of the population to represent the entire population (Polit & Beck, 2010). In this study, 15 women who came for review post mastectomy at selected tertiary hospitals surgical clinic were sampled using non-probability purposive sampling as they were knowledgeable about mastectomy. Purposive sampling involves identifying and selecting individuals that are especially experienced with a phenomenon of interest (Cresswell & Plano Clark, 2011). Sampling can also refer to choosing specific locations, times of days, various events, and activities to observe in fieldwork (Tracy, 2013). All women were of middle to senior age. The women were referred from the following district: Mopani = 3, Capricon = 6, Vhembe = 3, Waterberg = 01 and Sekhukhune = 2. Thirteen women were chosen from tertiary hospital number 2 because that is where the majority of the follow-up and reviews take place, whereas just two were chosen from tertiary hospital number 1, as shown in table 3.1.

Table 3.1: Identifying Data of the participants

Participants	Gender	Age	District	Number of weeks post mastectomy	Institution were sampling was done
P1	Female	49	Capricorn	12	Tertiary hospital 1
P2	Female	53	Mopani	14	Tertiary hospital 1
P3	Female	48	Mopani	16	Tertiary hospital 2
P4	Female	43	Vhembe	24	Tertiary hospital 2
P5	Female	40	Waterberg	214	Tertiary hospital 2
P6	Female	62	Mopani	52	Tertiary hospital 2
P7	Female	44	Capricorn	222	Tertiary hospital 2

P8	Female	34	Capricorn	156	Tertiary hospital 2
P9	Female	47	Capricorn	44	Tertiary hospital 2
P10	Female	35	Sekhukhune	84	Tertiary hospital 2
P11	Female	56	Capricorn	98	Tertiary hospital 2
P12	Female	36	Vhembe	120	Tertiary hospital 2
P13	Female	50	Capricorn	232	Tertiary hospital 2
P14	Female	63	Sekhukhune	52	Tertiary hospital 2
P15	Female	55	Vhembe	88	Tertiary hospital 2

- Inclusion criteria

All women who came for review at the two selected tertiary institutions surgical clinics who were post mastectomy 12 weeks and more were included and they were physically stable and not vulnerable. The reason for inclusion at 12 weeks was because all women were stable and had enough time to have gone through some of the challenges like complications, feeling of dependency and how people react towards them.

- Exclusion criteria

All women who were 12 weeks post mastectomy but unwilling and unable to participate were excluded in this study as participation was voluntarily.

3.6 DATA COLLECTION METHOD

Data collection process refers to the process where the researcher gathers information from the selected participants in order to answer the research question (De Vos, Delport, Fouche & Strydom, 2011). The purpose of data collection is to obtain information to keep on record, to make decisions about important issues, and to pass that information to others.

Recruitment of the participants

The researcher visited the selected tertiary hospitals after receiving permission to explain the outline of the study to the operational managers of the surgical and breast clinics. The operational managers introduced the researcher to the patients as well as the medical personnel. A nurse was also assigned to assist the researcher to identify all 12 weeks post mastectomy women. The researcher explain the outline, objectives and the significance of the study to all women who meet the criteria and they were invited to participate in the study. Those that were willing to participate signed the informed consent as explained and a date for data collection was set.

Data collection process

A Semi-structured one-to-one interview was used to collect data and each interview lasted roughly 45 minutes which was audio recorded using a voice recorder and field notes. The interviews were conducted in an area free from distractions at the Out Patient department. The central question asked was as follows: “please tell me in details, your experiences after having had the mastectomy operation”. The researcher also had probing questions (interview guide) that was used in an interview, to ensure that all question areas are covered.

Participants then came in one by one, the researcher greeted them, explained the interview process and what is expected of them, notified them again that it is voluntary and they may withdraw at any time. The questions were then asked, giving them time in between to even share a joke or take a break. The researcher nodded his head all the time and requested more clarity where there was a lack of understanding. Water for drinking was available and the interview did not take longer than expected as many of them had to be in time for the transport. By the time patient number ten was interviewed in the second week, saturation was reached. The researcher pushed on to number twelve but there was no new information. The researcher wanted to stop at this point only to find that three more were waiting outside. At the end, all the participants were thanked for their time and they were informed of the possibility of further contact with them should the need for clarity arise more especially those that needed to motivate other patients with breast cancer at the clinics. Data collection was done over a period of four weeks.

3.7 PILOT STUDY

In preparation for data collection, the researcher conducted pilot testing at tertiary hospital number one using semi-structured interviews with three women who had undergone mastectomy in order to detect possible flaws that could occur during the data collection process and rectify these (De Vos, Delport, Fouche & Strydom, 2011).

During the pilot study, the researcher discovered that the majority of women who underwent a mastectomy had their reviews and follow-up done at tertiary institution number two. As a result, the Polokwane/Mankweng hospital complex research ethics committee granted authorization to gather data on both tertiary institutions. The results for the pilot study was not included on the study and there were no changes required for data collection instrument. Those who were included in the pilot study were excluded during data collection.

3.8 DATA ANALYSIS

Data analysis is the systematic organisation and synthesis of research data. Qualitative data analysis is the organisation and interpretation of narrative data for the purpose of discovering important underlying themes, categories, and patterns of relationships (Polit & Beck, 2010). Tape interviews were transcribed verbatim immediately after the interview or the following day. The Colaizzi method (Polit & Beck, 2012) is used to analyse the data. The Colaizzi seven-step procedure for analysis is, according McCance and Mcilfatrick (2008), an appropriate data analysis framework for Husserlian phenomenological research.

The steps of the data analysis process were applied as follows (Polit & Beck, 2012):

Step 1: Read all protocols to acquire a feel for them.

All the transcribed interviews are read and reread until the researcher have a full understanding of the content.

Step 2: Review each protocol and extract significant statements.

After the researcher had a full understanding of the content and has highlighted significant statements in each transcribed interview using different colours; statements with similar problems experienced have one colour, continuing with different colours of highlighters for different problems experienced.

Step 3: Spell out the meaning of each significant statement.

At this stage, the researcher looks for the meaning of each colour code of the significant statements highlighted as in step 2.

Step 4: The researcher organises the formulated meanings into clusters of themes.

At this point, the researcher will have themes identified. Each major theme will have subcategories, which are clustered according to similar problems experienced.

Step 5: Integrate results into an exhaustive description of the phenomenon under study.

After identification of the major themes, the researcher gives a detailed description of the women's experiences after they had undergone mastectomy.

Step 6: Formulate an exhaustive description of the phenomenon under study in a statement of identification as unequivocal as possible.

While describing the women's experiences following mastectomy in relation to the identified themes, the researcher is able to add some narrative statements, which give identification, from participants having experienced the phenomenon under study

Step 7: Ask participants about the findings thus far as a final validating step.

The findings were presented to the participants and the researcher confirmed it to be a true reflection of their experiences relating to themes that had emerged from the transcribed interviews, which is also the phenomenon under study.

3.9. METHODS TO ENSURE TRUSTWORTHINESS

Polit and Beck (2010) describe trustworthiness as the degree of confidence that qualitative researchers has in their data. The four aspects of trustworthiness as outlined by Lincolin and Guba's model (as cited in Klass, 2013) to ensure reliability and credibility of qualitative research are: credibility, transferability, dependability and confirmability.

3.9.1 Credibility

Credibility ensured prolonged engagement in the research field where the researcher established a relationship of trust with the participants through the explanation of the research objectives and process. The credibility of the findings was ensured through triangulation, member checking and peer debriefing (Lincolin and Guba cited in Klass, 2013).

3.9.1.1 Triangulation

Polit and Beck (2008) describe triangulation as the use of multiple sources to draw conclusions with regard to what constitutes the truth. Semi -structured interviews were used and recorded using a voice recorder and field notes were taken to ensure triangulation. Triangulation strategy helped to compensate weaknesses of one method or technique of data collection with an alternative strategy (Cohen, Manion & Morrison, 2011).

3.9.1.2 Member Checking

The method of returning an interview or analysed data to a participant. Research participants were actively involved in checking and confirming the results to reduce the potential of research bias. Member checking was used to validate, verify, or assess the trustworthiness of qualitative results (Doyle, 2007). At this study, the interpretation of the results means that the analysed and interpreted data were resent or read to participants for them to evaluate the interpretations made by the inquirer and they were allowed to suggest changes if they were unhappy with the interpretation made by the researcher which were not what participants reported during interviews.

3.9.2 Dependability

Dependability in research is determined by the extent to which the study is consistent in its enquiry process which includes the techniques used in data collection, findings of the study, interpretations and recommendations of the study (Polit & Beck, 2012). Coded data was analysed by the researcher and the independent co-coder at with least one or two weeks' gestation period between each coding (Polit & Beck, 2012).

3.9.3 Transferability

It entails the extent to which qualitative findings can be transferred to other settings or groups (Polit & Beck, 2010). The sampling and the data collection method used enabled with the decision of the extent to which the findings may be transferred to other individuals and other situations (Tappen, 2011).In this study, the research study's findings may not be transferable because the experiences of the research participants for the current study might not be same with others.

3.9.4 Confirmability

Confirmability refers to the objectivity or neutrality of data and interpretations (Polit & Beck, 2010). Confirmability in this study was ensured by a Confirmability audit where the researcher verified data against recorded responses to conclude the findings of the study. This research was supervised by two qualitative researchers from the University of Limpopo who had access to both audio recordings and the field notes.

3.10 ETHICAL CONSIDERATIONS

3.10.1 Clearance certificate

The researcher obtained ethical clearance from the Turfloop Research Ethics Committee (TREC) of the University of Limpopo.

3.10.2 Ethical principles

Ethical principles adhered to in the study were through the following:

3.10.1. Permission

Permission to conduct the study was obtained from the Department of Health (Appendix B), Limpopo Province, as well as from the management of the two selected tertiary institutions where the study was conducted.

3.10.2. Informed consent

Informed consent ensures that the ethical principle of voluntary participation, the right of respect of human dignity, the right of self-determination and full disclosure are adhered to (Polit & Beck, 2014). Participants were informed about the purpose, objectives and significance of the study in the language they understood. The researcher explained to the participants that participation in the study was voluntary. The participants were notified of their freewill to participate in the study, and that they could withdraw at any time during the study even if they had previously given consent (Brink *et al.,* 2012). Written informed consent was obtained from every participant who signed and used a thumb print for those who were unable to sign. The consent forms were written in three local used languages and on in English. The researcher is fluent in local languages no interpreter was required. (See Annexure D for an example of signed consent).

3.10.3. Principle of Anonymity

To ensure anonymity, participants' information is not linked with the collected data, even by the researcher (Grove *et al.,* 2015). The participants' names were not used during data collection and data analysis. The names of the participants and the institutions were data was collected are not indicated in the report. The codes were used during the interview sessions instead of participants' real names. The researcher tried not to link the collected data with the participants' information, even during data analysis (Grove *et al.,* 2015).

3.10.4. Principle of Confidentiality and Privacy

Confidentiality occurs when the researcher cannot link the participant information with the collected data, and privacy ensures that the researcher is not more intrusive in participants' lives than s/he needs to be (Polit & Beck, 2012). Participant information, together with the interview records, were kept locked in the researcher's personal locker and there was no unauthorised person who had access to them. There was no need to share participants' information with other stakeholders other than the research team, and this was done with the participants' authorisation. The participants were assured that the information provided would not be used against them in anyway whatsoever (Grove *et al.,* 2015). Privacy was ensured by using a private room with a "no disturbance sign" on the door, when collecting data.

3.10.5. Principle of beneficence and non-maleficence

The principle of beneficence and non-maleficence is grounded in the premise that a person has a right to be protected from harm and discomfort and that one should do good and no harm (Botma *et al.,* 2015). In the study, the researcher ensured that an interview was stopped immediately when a case of discomfort arose, like when the participants bursts in tears and could no longer continue. Water was provided and a psychological consult was rendered. The researcher was a professional nurse trained to do counselling, therefore where necessary counselling was offered. There was no economic harm to the participants, as they were not requested to use their money in any way.

3.10.6. Principle of justice

The Principle of justice refers to the participants' right to fair selection and treatment (Brink *et al.,* 2012). The researcher was fair in selecting participants from the study population and the needs of research participants came before the objective of the study. The reason for selection was in relation to the purpose of the study, not due to manipulation or vulnerability. Participants were provided with clarity and explanations whenever they were requested from the researcher, regardless of their geographical location (Brink *et al.,* 2012). The researcher shared information equally amongst them on how they will be involved in the study and how they will not be involved to avoid being unjust to others.

3.11. BIAS

Bias according to Polit and Beck (2010) is an influence that produces an error in an estimate or an inference. In this study bias will be minimised by utilising multiple sources of data collection methods, adhering to the research methodology of the study, using the prepared interview guide and not adding own opinions. Purposive sampling was used to select people to participate in the study to select participants that had mastectomy for more than 12 weeks. It enabled the researcher to choose participants according to the knowledge of the researcher. The researcher used the language that was best understood by the participant to avoid elaborating on the participant's answers thus ending up putting words to their mouth.

3.12 CONCLUSION

Chapter 3 discussed the research approached used to achieve the study aim. The research designs that assisted the researcher to achieve the research objectives were discussed in this chapter. The accessible population whose experiences assisted the researcher to achieve the aim were described in one section of the current chapter. The researcher further described the method used to sample the population as well as the data collection and analysis methods. The last section of the chapter was related to elements taken by the researcher to achieve data quality. The next chapter discusses the findings obtained from the interviews with the participants

CHAPTER 4

RESULTS AND DISCUSSION OF THE FINDINGS

4.1 INTRODUCTION

Chapter 3 outlined the research methodology followed in this study which was a qualitative research method in the exploration of experiences of women who had undergone a mastectomy at Mankweng hospital in Limpopo Province. This chapter presents and discusses the research findings from the individual semi-structured in-depth interviews conducted with patients at Mankweng and Pietersburg hospitals. The purpose of the study is to explore and describe the experiences of women who had undergone mastectomy at Mankweng hospital in the Limpopo province, South Africa. To develop adaptation strategies for women who had undergone mastectomy based on the study results.

4.2 DATA MANAGEMENT AND ANALYSIS

The data which were collected during individual semi-structured in-depth interviews were analysed using the seven steps of Colaizzi’s open coding qualitative data analysis method as described by Creswell (2014) as outlined in the research methodology as described in Chapter three. Data were also submitted to an independent coder for coding. A consensus meeting was set between the researcher and the independent coder in order to discuss and agree on final themes and sub-themes based on the ones which emerged when analysing independently. The research questions that were used to guide the researcher were:

- How did you feel when you were told that you have breast cancer?
- What are your experiences after removing your breast?
- How did you perform your normal home duties after mastectomy?
- How do feel when you look at yourself and see that you are now with one breast?
- How was the support from family and relatives after mastectomy?
- How did you financially support yourself after mastectomy?
- How did you cope at home after mastectomy?

Table 4.1 Depicts the final themes and sub-themes which were agreed upon by the researcher and independent coder which serve as the findings of the study.

Themes	Sub-themes
Theme 1: Feelings after mastectomy	1.1: Feeling of being disabled 1.2 Feeling anxious 1.3: Feeling of acceptance
Theme 2: Challenges experienced	2.1: Physically 2.2: Financially 2.3: Institutional resources
Theme 3: Identified support systems	3.1: Family, partner and friends 3.2: Community support groups 3.3: Spiritually 3.4: Support by nurses and patients
Theme 4: Knowledge of breast examination	4.1: Clinics 4.2:Other (Media like radio, family, doctor)

4.3 FINDINGS FROM SEMI-STRUCTURED INTERVIEWS

This section captures the exploration of experiences of women who had undergone mastectomy at Mankweng hospital in Limpopo Province. The findings of the semi-structured interviews resulted in themes and subthemes. The themes and subthemes are supported by a literature control that reinforces the study results and participants' verbatim statements that are presented.

4.3.1 THEME 1: FEELINGS AFTER MASTECTOMY

Theme 1 is feeling after mastectomy comprising of three sub-themes. The findings show that participants in this study had negative as well as positive feelings after mastectomy. Some reported the feelings of being disabled, anxious, worried while others feel relieved after mastectomy.

4.3.1.1 Sub-theme 1.1: Feeling of being disabled

Feeling of being disables will be discussed to illustrate how women post mastectomy felt. The study finds that some women reported feelings of being disabled after the removal of the breast/s. Based on the study by Koçan and Gürsoy (2016), a woman represented femininity and it was essential for them to be presentable to their husbands when they put clothes on. Even if mastectomy is one of the treatments for breast cancer, it causes a change in the appearance of the breast thus causing a major effect on women's self-image and a decreased sense of femininity that can lead to anxiety and depression to such an extent that they avoid visiting public places (Jetha, Gul & Lalani, 2017). According to a study by Stecher, Cohen and Myburgh (2019), it is reported that women who had undergone mastectomy experienced shame. This was as a result of losing their breast which to them is was a symbol of beauty, sensuality and femininity thus playing a huge role in their self-image and value in society. Participants found hair loss devastating while others accepted it.

Some women reported to be worried when they see the scar in the mirror, this made them feel like their image has changed. This was corroborated by four participants who echoed that:

> "I felt like I am disabled." (Participant 5).
>
> "Eish, when I was bathing and going to the mirror, I was down and feeling like I am not the same person I was before." (Participant 12).
>
> ''It was difficult as I realise the situation of living with incomplete parts. '' (Participant 4).
>
> ''It is of course painful to see one with a single organ while one knows that one is born with two organs." (Participant 7).

Besides the concern about the feeling of being disabled, the participants also expressed the feeling of hiding the scar or themselves from other people and also their family members, as evidenced by:

> ''I felt like I could hide every time, so no one should see me." (Participant 12).
>
> ''I do not allow my children in the bathroom anymore because I do not want them to see what happened." (Participant 7).
>
> '' I did not go to the clinic; obvious all the people will know that I removed my breast.'' (Participant 5).

> ‘’ Even now, some of my children does not know that I am suffering from cancer.’’ (Participant 3).

4.3.1.2 Sub-theme 1.2: Feeling anxious or uncertain

The findings of the study also show that some women were concerned about the spread of the cancer to the other parts after mastectomy. They seem to be worried that the cancer might recur and spread, as evidenced by:

> “I mean if this thing comes back and spread to the other breast, what kind of person will I be. I just wish that this thing is gone away for good.” (Participant 7).
>
> ‘’ if it was not removed, there is a possibility that it is going to spread to the bones.’’ (Participant 2).

One woman in this study expressed a concern that removal of the breast/s might have an effect on having children. The woman had a feeling that mastectomy might affect her fertility. In addition, the woman had a feeling that breastfeeding with one breast might not be possible, as evidenced by:

> “It was difficult as I realised the situation of living with incomplete parts and imagining that I might not have children anymore nor breastfeeding with one breast.” (Participant 6).

The findings of the study show that women who had undergone mastectomy in the Limpopo province, Mankweng hospital experienced various feelings after mastectomy such as feeling of being disabled, feelings of hiding the scar, feelings or worried that the cancer might recur and spread. In addition to the different feeling women were also concerned that mastectomy might affect their infertility and breastfeeding. Heidari and Ghodusi (2015) support the aforementioned statements; they report that the impact of physical disability due to mastectomy on the body esteem was an important issue. After mastectomy, patients felt disabled and they could no longer felt attractive because their desired body images were gone due to one or both breasts being surgically removed. Study by Fallbjörk, Rasmussen, Karlsson & Salander (2013) found that society as a whole where these patients were living regarded physical attractiveness as essential for a woman, being without a breast made society to have a bad judgement on such a woman. Therefore, women post mastectomy regarded themselves disabled and no longer attractive. Anderson, Islam, Hodgson, Sabatino, Rodriguez, Lee and Nichols (2017) also report that women who underwent mastectomy felt disabled due to breast asymmetry. As a result of breast asymmetry, post mastectomy women's then felt less feminine and less sexually attractive more especially because they did not have breast reconstruction.

4.3.1.3 Sub-theme 1.3: Feeling of acceptance

During data collection, it was found that many women interviewed accepted their state of living with breast cancer and going through mastectomy process. It is being evidenced by the quotes below which is supported by the literature review:

> "I did not have stress because the way I was feeling, I felt like the breast was carrying a huge disease and there was no other way, maybe when removed, I will feel better and have a prolonged life, I took it like that. "(Participant 1).
>
> ''One needed not to give-up on breast cancer, if it does not have any function anymore and threatening my life, it does not help to keep it.'' (Participant 8).
>
> ''I did understand that I am not alone and it is a sickness, one needed to accept.'' (Participant 6).

The above quote is supported by three others below:

> "From the start my spirit was free because I knew that cancer kills, and that to remove my breast was the only way to be saved."(Participant 4).
>
> "I want to be healed. I felt like I am ok because I want to be healed. I accepted everything because I want to be healed."(Participant 5).
>
> '' I have accepted the condition and started to rejoice in its presence.'' (Participant 11).

Even after having the mastectomy and chemotherapy as a result of breast cancer, some women took advice from physicians more serious to regain their health. Some patients say they thanked God after the mastectomy and felt like they were born again and appreciating heath more than before thus accepting their state of going through breast cancer. They also stopped grieving because of accepting the condition

(Fouladi, Pourfarzi, Ali-Mohammadi, Masumi, Agamohammadi & Mazaheri, 2013). Other referred to support from nurses and physicians being valuable to assist them with coping and accepting the breast cancer condition (Robertson, Jeevaratnam, Agrawal & Cutress, 2017). As the data collection continued, more women who accepted breast cancer were found and they reported not to be troubled by breast cancer as evidenced below:

> "To be honest, I did not worry a lot because the Doctor who diagnosed me told me that it is curable when found at earlier stage, his words gave me courage that I will be cured."(Participant 2).
>
> "I did understood that I am not alone and it is a sickness that has come, and I want to save my life, had I refused maybe I would not be alive. I decided to agree on what was said I should do, one just has to accept." (Participant 8).

To support the quotes above, it was found during the study below that women with breast cancer never felt alone because they were supported which made it easier to accept the breast cancer diagnosis. Women who were diagnosed with breast cancer cited nurses in hospital as essential. Nurses made them to accept breast cancer diagnosis through contact sessions and they never felt alone. They valued the extra support they received from nurses and that knowing that a social worker was in place to offer extra support gave them peace of mind during time of distress.

Women reported that doctors and oncologist don't have much time to sit and talk and nurses were always there to answer their questions and satisfy their needs (Blaschke, Gough, Chua, Francis, Cockerell, Drosdowsky & Krishnasamy, 2019). In conclusion: Women who go through breast cancer and mastectomy can really cope well if people support them fully, starting from the hospital staff and lastly their families.

4.3.2 THEME 2: CHALLENGES EXPERIENCED

This section covers the challenges experienced by all the women who had undergone mastectomy. These challenges are explained in detail below as supported by the literature from the interviews according to different types of challenges faced by women who had undergone mastectomy.

4.3.2.1 Sub-theme 2.1: Physically

The literature mentioned below illustrate the physical challenges faced by women who had undergone mastectomy as quoted during the interviews:

> ‘’On my way home, I felt liquid going up and down on the operated side but the liquid was not coming out. When I arrived at the hospital, I was very swollen at the operation side. I could not rotate my arm totally.’’ (Participant 2).

Despite suffering from pain caused by the mastectomy procedure, patients went through chemotherapy pain which was physically challenging as illustrated below:

> ‘’Chemotherapy is very painful, you feel very dizzy and the other day I vomited for almost 2 days with no sleep. It always happened mostly when I forget the tablets meant to prevent nausea and vomiting.’’(Participant 2).

> ‘’I only felt pain and became sick when I was injected with chemo’s. It took one whole week without appetite and vomiting when I eat.’’ (Participant 8).

After receiving chemotherapy, some patients face challenges of experiencing visible necrosis of the skin, wound breakdown or discharges which then put them under anxiety and depression thus affecting their quality of life. Since being diagnosed with breast cancer is a serious challenge, going through the process of mastectomy is filled with a series of uncertainty post mastectomy, having a mastectomy and then necrosis becomes serious and a challenging setback postoperatively (Robertson, Jeevaratnam, Agrawal & Cutress, 2017). According to Brandberg, Sandelin, Erikson, Jurell, Liljegren, Lindblom, Lindén, Von Wachenfeldt, Wickman and Arver (2008), a study conducted on Swedish women showed that a substantial proportion of the women studied reported problems with body image 1 year after Bilateral Prophylactic Mastectomy (BPM), e.g. self- consciousness, feeling less sexually attractive, and dissatisfaction with the scars (Brandberg et al., 2008). After the surgery, many women described what they saw as “wretched, horrible, scary, ugly, crooked, collapsed shape”. However, the most commonly used description of their appearance was that they looked incomplete and half because they did not have a breast (Koçan & Gürsoy, 2016). Many women suffered from a negative body image post mastectomy. Though mastectomy is a surgical treatment for breast cancer, findings suggest that it may negatively affect a woman’s body image and her self-image (Koçan & Gürsoy, 2016).

4.3.2.2 Sub-theme 2.2: Financially

During data collection at the public hospital, it was found that the majority of the participants faced financial challenges which sometimes threated their check-ups. Patients were complaining about paying for files and transport from their own pockets and illustrated below:

> “The hospital is making us to pay. I pay R40 at Nkhensani hospital to take the file and do bloods, then R75 at Polokwane hospital. If they can send transport to collect us, we would benefit from it.” (Participant 2).
>
> “Yes, when one has done mastectomy you have to come to hospital several times, And if one does not finance what can one do, and when one is coming for...” (Participant 6).
>
> ‘‘The social grant the old lady is getting is too little to support us because I am not working. ‘’ (Participant 8).

As a developing country, South Africa faces challenges to meet health needs hence the aforementioned quotes are complaining about finances. The literature below highlights the financial situations that some developing countries are facing. Due to the increasing breast cancer around the world that goes with regularly check-ups and surgeries, health ministries and health-care systems in under developed countries are struggling to respond to the increasing morbidity and mortality from advanced cancers. Majority of the patients treated in the public system are from the urban poor, rural, remote and indigenous populations (Goss, Lee, Badovinac-Crnjevic, Strasser-Weippl, Chavarri-Guerra, St Louis & Liedke, 2013). Goss *et al.* (2013) report that the reason behind high mortality rate in rural areas is due to low breast cancer awareness. There is a lack of early detection with concomitant higher stage of disease at presentation, lack of an implemented, effective national screening programme for women and lack of timely access to optimal cancer care, all of which challenge the ability of these under developed countries to ameliorate their breast cancer burden.

As a result of undergoing significant economic growth, many developing countries are rapidly going through socioeconomic changes. Low developing countries are thus facing an increasing challenge to gain an understanding of the specific circumstances and criteria in which they would consider launching breast cancer screening programmes due to their insufficient socioeconomic status and low cancer awareness, which then make mammography screening programmes of insufficient utility (Goss, Strasser-Weippl, Lee-Bychkovsky, Fan, Li, Chavarri-Guerra & Chen, 2014).

Other quotes from the participants complaining about distance and money which is hard for them during the breast cancer process which requires too many visits to the hospital:

> “We do pay for files, they say we are owing money here, this is what surprised us because we were not told from the start. I do not know that credit because did not ask whether the credit started with the chemo’s or not because that money is too much, it is about two thousand.” (Participant 15).
>
> “Seeing that the transport is costly when going to and from local hospital.” (Participant 8).
>
> “...because we come from far and it costs as you pay to reach your local hospital for transport”. (Participant 12).

The literature below also highlights how the population struggle due to lack of transportation and financial limitations:

The distance the target population must travel to hospitals with their poor socioeconomic background and the waiting period for mammography screening had an impact on the adherence rate of the mammography programme. Due to lack of transporting, financial limitations and lack of medical insurances, countries like the United States wish to have mobile mammography instruments to overcome challenges faced by low developing countries (Carkaci, Geiser, Adrada, Marquez & Whitman, 2013).

4.3.2.3 Sub-theme 2.3: Institutional resources

One of the challenges faced by women in public hospitals is the lack of resources to treat them. During data collection, it was found that lack of resources delayed diagnosis for some of the women as quoted below:

> ‘’I was transferred and told by them that the Mammogram machine is not available is damaged, I was told to go back home and come back at another

> date. I have been coming back to Voortrekker and turned back again for over a period of about six months.'' (Participant 3).

Studies below also support the quote above regarding the impact of having no mammogram machines to diagnose breast cancer at an earlier stage:

Ramirez, Pérez-Stable, Talavera, Penedo, Carrillo, Fernandez and Nápoles (2013) report that there is strong evidence from clinical trials that regular screening mammography reduce mortality. This was because mammography assisted with early detection of breast cancer thus facilitating early treatment. Therefore, any time delay in using mammogram screening to detect breast cancer may have a critical impact on breast tumour size, stages, treatment and survival of subsequent breast cancer. Wubker (2013) reports that an effective mammographic screening programme was considered to be the best tool available for early stage detection of breast cancer and to reduce the risk of death due to breast cancer. Lee, Liedke, Barrios, Simon, Finkelstein and Goss (2012) report that it is important to keep the mammography machines up to a high standard by maintaining them. They reported that 20% of the facilities in Brazil have mammography machines that are broken and not in use.

Li and Shao (2015) refer to mammography screening as one tool that can promote early detection to downstage breast cancer diagnosis and mortality reduction. They report that because people will get diagnosed at earlier stages, they will stand a better chance of survival. Since some of the developing countries are facing economic challenges, improving their socioeconomic conditions, making use of the limited resources available due to poverty and increasing educational level of the population can also be the best methods which can drastically increase breast cancer awareness to all (Li & Shao, 2015).

4.3.3 THEME 3: IDENTIFIED SUPPORT SYSTEMS

4.3.3.1 Sub-theme 3.1: Family, partner (husband) and friends' support

During the journey of being diagnosed with breast cancer, the patient goes through the process of undergoing a mastectomy, radiations and chemotherapy which is emotionally and physically demanding. Therefore, support from immediate family, partner and friends becomes crucial in coping with breast cancer and it is thus supported by the following quotes:

> “My mom said, ’my child do not be scared, scared even to confess’. Even when I have friends I used to confess, that I have one breast, and even advised them that because you are women should know what they should do”.(Participant 4).

> “My family and my colleagues and they all supported me.” (Participant 2).

The following literature supports the aforementioned quotes regarding support from family members including relatives; Taha, Al-Qutob, Nyström, Wahlström and Berggren (2012) report that family support appeared to be a motivator that enabled women to overcome their ambivalence towards seeking breast health care as everyone around the family was there to support them. The women mentioned above appreciated receiving encouragement from their husbands, that was more appreciated when their daughters and sons booked the appointments and took their time to escort them to the mammography unit for check-up.

Due to commitments and support to women with breast cancer, some family members even cut their hair as a support to women going through chemotherapy (Taha, Al-Qutob, Nyström, Wahlström and Berggren, 2012). Bigatti, Brown, Steiner and Miller (2011) also support the study by Taha *et al.* (2012) by reporting that husbands of women with breast cancer were involved in providing care for their wives by dressing them, collecting medicine and organising doctors’ appointments. Other quotes to show the continued support from partners and family are quoted below:

> “My husband is the one that supports me mostly, he supports me when I start to be worried.” (Participant 5).

> “Oh, in my home, my siblings, my sisters and my younger brothers they were so supportive.” (Participant 6).

During data collection, the researcher received more and more positive responses regarding support from families as quoted above hence literature as quoted below; The research study by Kinsinger, Laurenceau, Carver and Antoni (2011) highlight that a patient that was going through breast cancer and mastectomy, her partner’s availability was vital and influential to her well-being. They further state that having a supportive partner, family and friends were always crucial for the woman going through breast cancer and aided in speedy recovery. Evidence to the aforementioned was stated by Soriano, Otto, Siegel and Laurenceau (2017) who report that one woman never thought her husband could love her again post mastectomy and yet he did. The love that the woman with mastectomy received post mastectomy was enabled by high-quality relationship they had before breast cancer diagnosis. Couples then reaffirmed their affection towards each other and lived on very well (Soriano, Otto, Siegel & Laurenceau, 2017).

Fouladi, Pourfarzi, Ali-Mohammadi, Masumi, Agamohammadi and Mazaheri (2013) report that families are important as they provide assistance with how to meet the basic needs of breast cancer patients post radical mastectomy, the needs which include food that contain high nutrition to promote wound healing post mastectomy. Availability of family members to people who have undergone mastectomy was important in providing psychological support, encouragement, love, and empathy to the patients while they were waiting during for chemotherapy sessions. They further state that patients who received support from their families always gave them a positive response during research interviews (Fouladi, Pourfarzi, Ali-Mohammadi, Masumi, Agamohammadi and Mazaheri, 2013).

4.3.3.2 Sub-theme 3.2: Community support groups

Women who go through breast cancer in Limpopo lack support groups where they can engage with each other and have someone like a breast cancer survivor to talk to. A breast cancer survivor or someone who had gone through breast cancer before is essential in motivating the newly diagnosed breast cancer women and thus allaying anxiety as quoted below:

> “Such support group is necessary as we will be able to advice and counsel one another that is where we would share information. You may find one deeply worried, even if these sicknesses will not kill one, but only the lack of support may kill one. So we need such support group.” (Participant 5).
>
> Another participant stated the same desire for a cancer survivor to motivate them:
>
> “We must meet with other cancer survivors and those who are still on treatment; it will motivate us to know that we are not alone.” (Participant 2).

To support the quotes above, literature below highlights similar desire regarding breast cancer survivors as mentioned below;

Taha, Al-Qutob, Nyström, Wahlström and Berggren (2012) found that some of the women in their study had a wish that, it would be better and more valuable to them if women who actually had survived breast cancer before could come to participate in the breast health promotion activities and instil hope to their lives.

That is supported by the following quote from their study: “There should be a woman who has been cured after detecting her breast cancer early and receiving treatment for it, this would provide me with hope, as I would prefer to die and be buried in one piece than being cut and sold by kilo”, (Taha, Al-Qutob, Nyström, Wahlström & Berggren, 2012). If there can be a breast cancer survivor as facilitator in a traditional group, it can be instrumental in providing participants with the necessary skills needed to cope with the daily problems associated with a breast cancer diagnosis; a breast cancer survivor has the power to empower participants in a support group (Power & Hegarty, 2010).

As data were collected, more women in Limpopo provinces spoke more about a support group as a whole in order for it to be beneficial to the community of Limpopo and giving people with breast cancer the chance to express themselves and get comfort from one other who had been diagnosed with breast cancer before as indicated below:

> “Support group will be relevant as it would help others to cope and be informed.” (Participant 12).
>
> “Yes I think it can be best for women to form a support group so they can be aware of the breast cancer. We can be able to sit in a support group and discuss problems that women experience, they will be able to know what life of a woman is like, and a woman must take care of herself.” (Participant 6).

Some studies also indicate the positive impact a support group has around the world and it is illustrated in the literature quotes below. Traditional support groups have been continually used to improve the health and well-being of individuals with breast cancer over the past several decades (Bender, Katz, Ferris & Jadad, 2013). Support groups do not compensate for the lack of support that family members or relatives can fail to give breast cancer patients, but they do have a positive impact on their well-being and allay anxiety levels (Houlihan & Tariman, 2017).

Namkoong, McLaughlin, Yoo, Hull, Shah, Kim and Gustafson (2013) demonstrate that lack of both supportive exchange and communication about an individual's cancer experience serves as a negative stressor on the body of the woman going through breast cancer thus adversely affecting her physical wellbeing. Through communication and support through a support group, individuals suffering from breast cancer bond with each other which have a positive effect amongst them. Lepore, Buzaglo, Lieberman, Golant, Greener and Davey (2014) also mention that because support groups encourage free exchange of feelings and emotional disclosure among participants, it might prove to be more beneficial to women with breast cancer.

Houlihan and Tariman (2017) state that introducing individuals to a support group at the time of diagnosis could allow them to obtain support almost immediately or allow them to access a group at their own pace. Reinforcing their options throughout their treatment and survivorship phases could also optimise an individual's support throughout their diagnosis. When someone is newly diagnosed with breast cancer, that is before going through all the processes like chemotherapy and mastectomy, introducing those individuals to a support group could allow them to obtain support almost immediately or allow them to access a group at their own pace without pressure (Houlihan & Tariman, 2017).

4.3.3.4 Sub-theme 1.3: Spiritually

As women who go through mastectomy faces many challenges and need support from all spheres, spiritual support is also of paramount importance to give these women hope to cope under the stress of breast cancer. One of the participant is quoted below regarding support from church:

> ‘’ I did accept that these are God's issues.’’ (Participant 8).
>
> ‘’ My spirit was that to remove the breast, I cast everything to God.’’ (Participant 4).
>
> ’ I am in this situation because of the reason God knows better.’’ (Participant 7).
>
> ‘’ I thank the grace of God and believed that God did these.’’ (Participant 11).

The studies below support the quote above with regard to church support. Coming to spirituality, families helped the patient who had undergone a mastectomy and worrying about breast cancer to meet the spiritual needs. They have done so by praying with them thus advising them not to despair (Anggraeni & Ekowati, 2011). Fouladi *et al*. (2013) state that, post mastectomy women who were religious in nature believed that God assisted them to consent for mastectomy. They believed that it was by divine fate that they have breast cancer and must just get along with it.

According to Ursaru, Crumpei and Crumpei (2014), there are many misconceptions around mastectomy which makes patients with breast cancer feel less satisfied with their health and lives in general. Therefore, religion became an important coping strategy as they faced breast cancer which is life threatening. Zamora, Yi, Akter, Kim, Warner and Kirchhoff (2017) support the aforementioned as they also state that religion and spirituality contribute immeasurably to the lives of women diagnosed with breast cancer.

Support from church members is of paramount importance as supported by the quotes below:

> ‘’I just told myself to accept, even get courage from church.’’ (Participant 3).
>
> ‘’ I was being helped by the church members that I am attending with.’’ (Participant 1).

4.3.3.4 Sub-theme 1.4: Support by nurses and patients

Some patients received support from health staff and some from patients which was best to allay anxiety regarding breast cancer as illustrated below:

> ‘’Helped by other sisters from Mankweng hospital who comforted me that organs used to be removed even if you are born with complete organs, some are born without other organs.’’ (Participant 3).
>
> ‘’Other patients in the ward were the ones that motivated and supported me, because if these people were alive, it meant I would still be alive.’’ (Participant 4).

To support the interviews stated above, other patients also reported an overall positive impression of their care. However, they were least satisfied with the amount of information and emotional support they received during their breast cancer chemotherapy. The reason for lack of information and emotional support was insufficient from staff in medical oncology (Droog, Armstrong & MacCurtain, 2014).

4.3.4 THEME 4: KNOWLEDGE OF BREAST EXAMINATION

4.3.4. 1 Sub-theme 1.2: Other (Media like a radio, family, doctor)

In this study, it was also found that women gained a lot of knowledge regarding breast cancer from the radio and some from doctors as quoted:

> "Doctors tell us what we should do, especially after menstruation, that you should examine your breasts by pressing them to check if there are no lumps inside." (Participant 4).
>
> "I heard about breast-self-examination from Munghana lonene FM, they have days where they teach about health. They taught us that we must do breast self-examination twice a day and also explained how we must do it? If it was not because of the lessons on the radio, I would have just said it is a small lump that can pass." (Participant 2).
>
> "While I was sweeping listening to the radio, there was a radio presenter who hosted a doctor who presented about the mammogram. During all these times I knew that my breast had something when I touched it.'' (Participant 12).

Taha, Al-Qutob, Nyström, Wahlström and Berggren (2012) report that women talked about seeing or hearing about breast cancer and breast health examinations on television, radio, billboards, doctor's clinics and newspapers. Then further went on to report that these women also spoke about attending lectures regarding breast cancer at a nearby NGO. When coming to breast self-examinations, these women were taught by a physician in the maternity and child health care centres. Some participants were relieved to also see breast cancer outreach women visiting them in their homes. After such visits by breast cancer outreach women, women with breast cancer reported that their fears were soothed and they acquired more skills about breast cancer and knowledge on how to practise breast health examinations (Taha, Al-Qutob, Nyström, Wahlström & Berggren, 2012).

Despite gaining knowledge about breast self-examination from the radio, clinics and doctors, more effort should be put in place like doing a lot of community outreach thus teaching the community about breast cancer and breast self-examination, including schools.

4.4 INTEGRATION OF THEORY (ROY’S ADAPTATION MODEL) AND RESULTS OF THE STUDY

The research uses Roy’s theory of adaptation as a theoretical framework to analyse the experiences of women who had undergone mastectomy. Roy's theory defines adaptation as the process by which an individual or group makes conscious choices to cope with his or her situation (Sherman, 2013). In the current study findings, majority of mothers reported the feeling of being relieved and acceptance after mastectomy as an adaptive process of the diagnosis. The following major concepts according to Roy’s theory were applicable in the study findings as reported by the mothers:

4.4.1 Person

Roy defines a person as a recipient of nursing care and should be viewed as a holistic adaptive system (George, 1999). In this study the person was fifteen (15) women who had undergone mastectomy from the five districts in Limpopo Province. The women’s in the current study findings indicated different personnel that assisted them to cope with the diagnosis of breast cancer and its intervention. For example, the current study findings reported family members, partners and friends who played part in the process of adaptation. Thus suggesting that these women’s could not have coped and adapted without the mentioned personnel with the diagnosis of breast cancer.

Women’s in this study has to undergo four adaptive mode as per Roy’s theory which are:

- **Physiological mode**- In this study, the breast as an organ as a whole including the lobules, ducts and connective tissue are affected by cancer and mastectomy itself, women has to adapt to living without one or both breasts for the sake of good health. After mastectomy the women reported visible necrosis of the skin on the operated area, wound breakdown or discharges, chemotherapy pain which then put them under anxiety and depression thus affecting their quality of life. Other women were worried that the cancer might recur and spread. In addition to the different feeling women were also concerned that mastectomy might affect their infertility and breastfeeding. Despite the physiological challenges related to Brest cancer, the feeling of being relieved from pain after mastectomy was also reported.

- **Self-concept mode**- In this study, women's self-concept mode is how the felt post mastectomy and how they interacted with others. Women's felt like they were disabled and had to hide the operated side in order to feel normal and be able to interact with others without feeling of low self-esteem. Many women interviewed accepted their state of living with breast cancer and going through mastectomy process.
- **Role function mode**-In this study, role function mode for the women's who had undergone mastectomy were how they performed expected daily duties within their household and society. Some were still able to do light duties like peeling cabbages during funerals in their villages post mastectomy. The participants in this study reported to have gained a lot of knowledge regarding breast cancer from the radio, clinic and some from doctors which relieved fears and they acquired more skills about breast cancer.
- **Interdependence mode-** In this study , interdependence mode for women's who had undergone mastectomy was feeling valuable again , being loved and be able to love again and able to perform some duties without depending to anyone. During the journey of being diagnosed with breast cancer, the women goes through the process of undergoing a mastectomy, radiations and chemotherapy which is emotionally and physically demanding. Therefore, support from immediate family, partner and friends, community, spiritual and health practitioners becomes crucial in coping with breast cancer

4.4.2 Environment

Roy (2011) defines environment as all conditions, circumstances, and influences surrounding and affecting the development and behaviour of persons and groups. The individuals are in constant interaction with a changing environment that requires the individual to adapt. The environment for the women's who had undergone mastectomy has to be the society they live in, Polokwane/Mankweng hospital complex and the process they went through because of mastectomy on those environment.

Therefore, the current study findings indicate that although being challenged with the physical being, finances and lack of some institutional resources, influences from the media, community support and spiritual groups within the community played a critical role in women's adapting to the whole process of breast cancer.

4.4.3 Health

Roy defines health in terms of a continuum from death to the highest level of wellness. Health and illness are viewed as inevitable dimensions of the individual's life. The current study findings indicate a contrast perspective from women's who reported being unable to accept their state of disability post-Mastectomy, and such was aggravated by the feeling of anxiousness which affected their state of health as a whole.

4.4.4 Nursing

The goal of nursing is to promote adaptive responses in relation to the four adaptive modes. The goal of nursing is to promote the person's adaptation in his physiologic needs, his self-concept, his role function and his relation of interdependence during health and illness. According to Roy (2011), to the nurse acts as an external regulatory force to modify stimuli affecting adaptation. However, the current study indicates that the adaptive process was not only promoted by nurses during their hospitalization with breast cancer. Women's reported also that doctors and other patients in the same ward promoted the adaptation process during hospitalisation.

4.5 CONCLUSION

This chapter discussed the findings obtained from women who had undergone mastectomy in Limpopo Province. The researcher applied Colaizzi's open coding method to make sense of the collected data. The data analysis method assisted the researcher to generate four themes from the experiences of women who had undergone mastectomy. The themes include expressions about mastectomy that include feelings of being disabled, and acceptance of body changes; the existence of support systems for all women. The next chapter summarises the study while making recommendations based on the findings.

CHAPTER 5

SUMMARY, LIMITATIONS, MEASURES, RECOMMENDATIONS AND CONCLUSION

5.1 INTRODUCTION

The previous chapter discussed the findings regarding experiences of women who had undergone mastectomy at Mankweng hospital in the Limpopo province. This chapter summarises the findings of the study. It also indicates the extent to which the objectives of the study have been met and makes recommendations drawn from the findings of the study as discussed in chapter 4. Strategies are developed to assist women who had undergone mastectomy in Limpopo province to cope with conditions of breast cancer.

5.2 SUMMARY OF THE STUDY

5.2.1 Restatement of the aim of the study

The aim of the study was to determine the experiences of women who had undergone mastectomy at Mankweng hospital in the Limpopo province, SA. To achieve the aim, the researcher adopted a qualitative research approach with explorative and descriptive research design. The population that assisted in achieving the aim were the targeted population that had undergone mastectomy in Limpopo Province. Semi-structured interviews with a guide were implemented to collect and obtain data necessary to develop strategies to support the women. Colaizzi's method for data analysis was used to analyse data.

5.2.2 Restatement of the objectives of the Study

- To explore and describe the experiences of women who had undergone mastectomy at Mankweng hospital in the Limpopo province, SA. This objective was achieved as outlined in the summary of the findings (section 5.4).

5.2.3 Summary of findings of the study

The findings of the study are summarised below:

- **Theme 1: Feelings after mastectomy**

The study findings indicate that most of the women expressed the feeling of being disabled after mastectomy. While the other women expressed the feeling of acceptance post mastectomy, thus indicating a mixed expressions of women regarding mastectomy. The findings could be interpreted as an indication for psychological support to women who has undergone Mastectomy.

- **Theme 2: Challenges experienced**

The study findings report on the challenges experienced by women post-mastectomy. These challenges relate to the physical being, financially status, and also institutional resources that are used to care for the women. The findings therefore, suggest a need for support to both the women and institutions regarding the care of women post-mastectomy.

- **Theme 3: Identified support systems**

The study findings highlight the support system needed by women who had undergone mastectomy. Such support system includes family, partner and friends, community support groups and support by nurses and patients.

- **Theme 4: Knowledge of breast examination**

The study findings highlight that despite the challenges experienced, women demonstrated knowledge about breast examination which is significant for prevention of breast cancer.

5.3 MEASURES TO ASSIST WOMEN WHO HAD UNDERGONE MASTECTOMY IN LIMPOPO PROVINCE TO COPE WITH CONDITIONS OF BREAST CANCER

The section below indicates the strategies to assist women who had undergone mastectomy in Limpopo Province to cope with conditions of breast cancer. The strategies are based on the experiences of women who had undergone mastectomy in Limpopo Province.

5.3.1 Face-to-face clinical psychological consultation sessions followed by monthly group therapy for 6 months.

Sub-theme 1.1 and 1.2 which are feeling disabled and feeling of acceptance.

Surgeons need to refer post mastectomy patients to clinical psychologists 2 weeks post operatively to have a one-on-one session with a psychologist. The date for a psychological consultation must be when they return for review to avoid patients going to hospital on many days. The surgeon needs to provide the psychologists with all the details of the patient for tracking purposes. The reason for stating only one face-to-face session is because Limpopo Department of Health lacks clinical psychologists as the researcher struggled to get one during interviews.

Following the one-on-one clinical psychologist consultation, the clinical psychologist will then introduce the patient to a support group which will be for group counselling therapy which the psychologist will facilitate on a monthly basis. Nurses at tertiary hospital must initiate a monthly group therapy for these women to meet during mastectomy reviews as they are from different arears, the best chance to meet together is when they come for check -ups. The importance of the support group is the likelihood of meeting people with a common purpose, people who may understand each other better as they went through some of the same challenges**.** The feeling of loneliness at home gets to be attended to which may reduce stress, depression, being judged or feeling isolated.

5.3.2 Forming Breast Cancer Support Groups in Limpopo Province in different institutions and Breast Cancer Survivors motivational talk on local radio stations.

Another strategy for feeling of acceptance is for Limpopo Department of Health to form support groups using social workers. Social workers will then facilitate the establishment of the support group which must have breast cancer survivors or people that already went through breast cancer. These support groups will allow members to share their experiences on breast cancer and the mastectomy procedure itself thus giving newly diagnosed and operated on patients a moment of hope in coping with breast cancer. If it is not possible to start at different institutions, support group can best be formed at a tertiary hospital where they go for check-ups.

5.3.3 Reduce pain for all post mastectomy patients.

Sub-theme 2.1 Physical challenge

The Department of Health should ensure that pain medication is always available for post mastectomy patients which should be enough for two weeks and can be reduced to a lower schedule with time to avoid drug dependency. Doctors should assess patients thoroughly before discharge; they should check the stiches and accumulation of fluid on the mastectomy side, and they should give health education together with the nurses regarding aseptic care for the operated site. Nurses should always check post mastectomy patients for pain on the operated side and manage accordingly.

5.3.4 Disability grant for mastectomy patients from a disadvantaged background.

After mastectomy, the majority of women who underwent mastectomy are no longer able to perform their daily tasks to perfection, those who were employed are no longer able to perform tasks especially hard physical labour. Therefore, a social worker referral is essential by the doctor post mastectomy to arranger for a social disability grant. The period of the grant will depend on the social worker's assessment together with the doctor as they will check the regulations for granting such grant from government treasury. Those who are still young and able to resume to work can start with light duties at work until they are able to function to full capacity.

5.3.5 Decentralise the mastectomy procedure to regional hospitals in a form of outreach and have mammography X-ray machine available at all 3 regional functioning hospitals.

Sub-theme 2.2 Institutional resources

Limpopo Province depends on Mankweng/Polokwane hospital complexes for mastectomy services and breast cancer as a whole. Limpopo Department of Health must have more specialists that are able to operate in for instance Letaba hospital, Tshilidzini and Mokopane to reduce the burden placed on Mankweng/Polokwane hospital complexes. To train more Doctors, physiotherapists and Oncology nurses on Breast cancer and mastectomy to work in regional hospitals will improve the health care of breast cancer patient.

5.3.6 Breast Cancer support and guidance messages on local community radio stations, schools and family counselling.

For identified support system theme 3: Limpopo Department of Health should have nurses knowledgeable about breast cancer to give support messages and may do it anonymously also using breast cancer survivors and guidance through local community radio stations. They should motivate families living with breast cancer people to continue their caring and support. Psychologists should offer family counselling as well to families living with breast cancer patients as the word ‘cancer’ scares a lot of people.

5.3.8 Awareness campaign for self-breast examination

For theme 4: Professional Nurses in the surgical (Oncology) clinic at Polokwane /Mankweng complexes should organise self-breast examination awareness during the breast cancer month every year in the hospital OPD, shopping complex, and community to educate women on how to assess any breast lump. In addition presentations on radios and TV and pamphlets in all languages can be given to the community.

5.4 RECOMMENDATIONS OF THE STUDY

5.4.1 Nursing Practice

- The study findings demonstrate a need for sustaining the support to the women to enhance the better feeling after mastectomy. The researcher believes that the support can only be sustained when there is a collaborative effort from the patient, healthcare workers, family members or spouse and psychologists.
- All women diagnosed with breast cancer need to establish a strong support system during the diagnosis stage that could impact on the surgical intervention implications.

5.4.2 Nursing Research

- The study recommends further studies that could test and validate the developed strategies to women who had undergone mastectomy in Limpopo and the whole of South Africa.

5.4.3 Nursing Management

- Disseminate the findings of the current study to the Limpopo Department of Health senior committee in order to address the sensitive matter of mastectomy with dignity at senior level.
- The Limpopo Department of Health should have more trained oncology nurses to deal with status of patient's pre and post mastectomy.
- Limpopo Department of Health should have a programme through social workers that will deal with women who had undergone mastectomy especially in terms of employment and food support.

5.4.4 Nursing Education

- Nurses to create a health programme at primary health care to educate women about breast cancer screening and how to do breast self- examination.

5.5 Limitations of the study

Women who were interviewed were always not fully concentrating as they feared to be left behind by transport to their relevant hospitals.

The study was conducted with women who had undergone mastectomy at selected two tertiary institutions in the Limpopo Province only, and the reason for this was a lack of funding and a limited study period. Therefore, the study findings cannot be generalised to other hospitals within and outside the Limpopo Province of South African.

Furthermore, the study used a qualitative research approach to determine the experiences of women who had undergone mastectomy and as such, the findings cannot be generalised to other studies which used quantitative or a mixed method research approach.

5.6 CONCLUSION

The study aimed to determine the experiences of women who had undergone mastectomy. To achieve the aim, the researcher applied a qualitative research approach with explorative and descriptive design to answer the research question. Data were collected from women using a semi-structured interview as tool.

The data were analysed using Colaizzi's open coding method of data analysis. The findings indicate that women who had undergone mastectomy expressed the feeling of being disabled, while others accepted the changes in their body.

Those who accepted the changes could be because of the described existence support from the health care settings, community and healthcare providers. The researcher concludes that a strong collaborative team, that includes, oncology nurses, doctors, psychologists and family members is significant to maintain the optimum health of the women.

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LIST OF ANNEXURES

ANNEXURE A: TREC CERTIFICATE

University of Limpopo
Faculty of Health Sciences
Private Bag X1106, Sovenga, 0727, South Africa
Tel: (015) 268 2149, Fax: (015) 268 2865, Email:Kgagabi.letsoalo@ul.ac.za
Website: www.ul.ac.za

TO: **D Mnisi (201001693)**

FROM: **Mr KJ Letsoalo**

Chairperson: Faculty Higher Degrees Committee

DATE: **03 October 2017**

SUBJECT: **Research Proposal Corrections from FHDC (MNURS)**

Dear D Mnisi

I have pleasure in informing you that your Masters Research proposal served at the Faculty Higher Degrees meeting on the **02nd of October 2017** and your proposal need to be corrected as follows:

The main issues for corrections were:

- Proof read the whole document
- Remove bold under table of contents
- Page 1, all authors to be cited for the first time before (Jetha et al 2017)
- Page 2, rephrase the 2nd last paragraph
- Page 9, include bullets
- Page 13, rephrase data collection method
- Purpose to be aligned with the significance and define qualitative approach
- Include Tshivenda guide and correct Sepedi guide
- Update timeframe and remove budget
- Re-look at referencing and spacing

The corrected research proposal to be submitted to supervisor by the 06th of October 2017

Yours faithfully

Mr KJ Letsoalo

Chairperson: Faculty Higher Degrees Committee

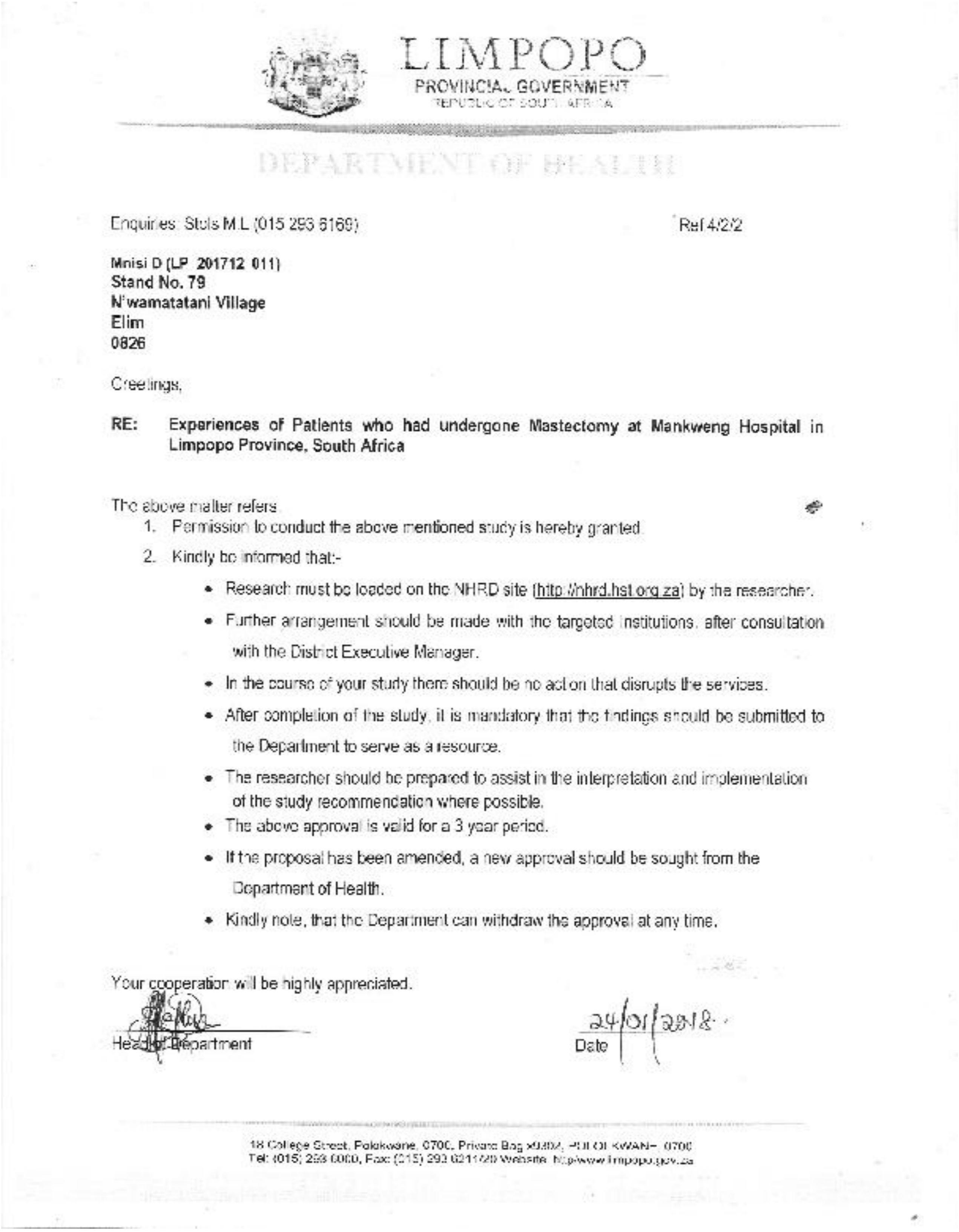
CC: Supervisor: Mrs GO Sumbane

Co-Supervisor: Prof TM Mothiba

UNIVERSITY OF LIMPOPO
FACULTY OF HEALTH SCIENCES
2017 -10- 03
PRIVATE BAG X1106
SOVENGA 0727

Finding solutions for Africa

ANNEXURE B: DOH PERMISSION



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Stols M.L (015 293 6169) Ref 4/2/2

Mnisi D (LP 201712 011)
Stand No. 79
N'wamatatani Village
Elim
0826

Greetings,

RE: Experiences of Patients who had undergone Mastectomy at Mankweng Hospital in Limpopo Province, South Africa

The above matter refers.

1. Permission to conduct the above mentioned study is hereby granted.
2. Kindly be informed that:-
   - Research must be loaded on the NHRD site (http://nhrd.hst.org.za) by the researcher.
   - Further arrangement should be made with the targeted institutions, after consultation with the District Executive Manager.
   - In the course of your study there should be no action that disrupts the services.
   - After completion of the study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
   - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
   - The above approval is valid for a 3 year period.
   - If the proposal has been amended, a new approval should be sought from the Department of Health.
   - Kindly note, that the Department can withdraw the approval at any time.

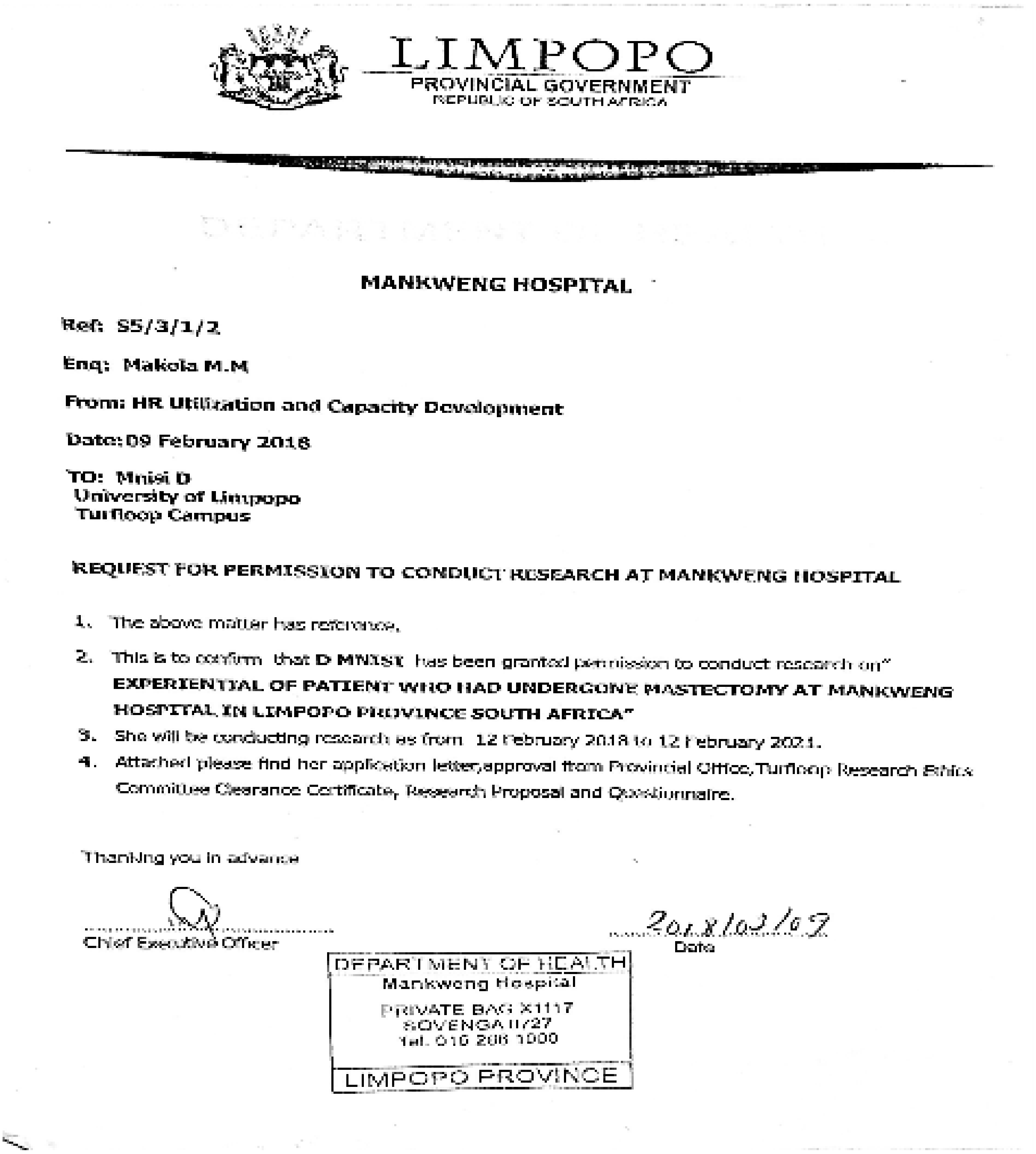
Your cooperation will be highly appreciated.

Head of Department

24/01/2018
Date

18 College Street, Polokwane, 0700, Private Bag x9302, POLOKWANE, 0700
Tel: (015) 293 6000, Fax: (015) 293 6211/20 Website: http://www.limpopo.gov.za

ANNEXURE C: MANKWENG HOSPITAL PERMISSION



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

MANKWENG HOSPITAL

Ref: S5/3/1/2

Enq: Makola M.M

From: HR Utilization and Capacity Development

Date: 09 February 2018

TO: Mnisi D
University of Limpopo
Turfloop Campus

REQUEST FOR PERMISSION TO CONDUCT RESEARCH AT MANKWENG HOSPITAL

1. The above matter has reference,
2. This is to confirm that **D MNISI** has been granted permission to conduct research on" **EXPERIENTIAL OF PATIENT WHO HAD UNDERGONE MASTECTOMY AT MANKWENG HOSPITAL IN LIMPOPO PROVINCE SOUTH AFRICA"**
3. She will be conducting research as from 12 February 2018 to 12 February 2021.
4. Attached please find her application letter,approval from Provincial Office,Turfloop Research Ethics Committee Clearance Certificate, Research Proposal and Questionnaire.

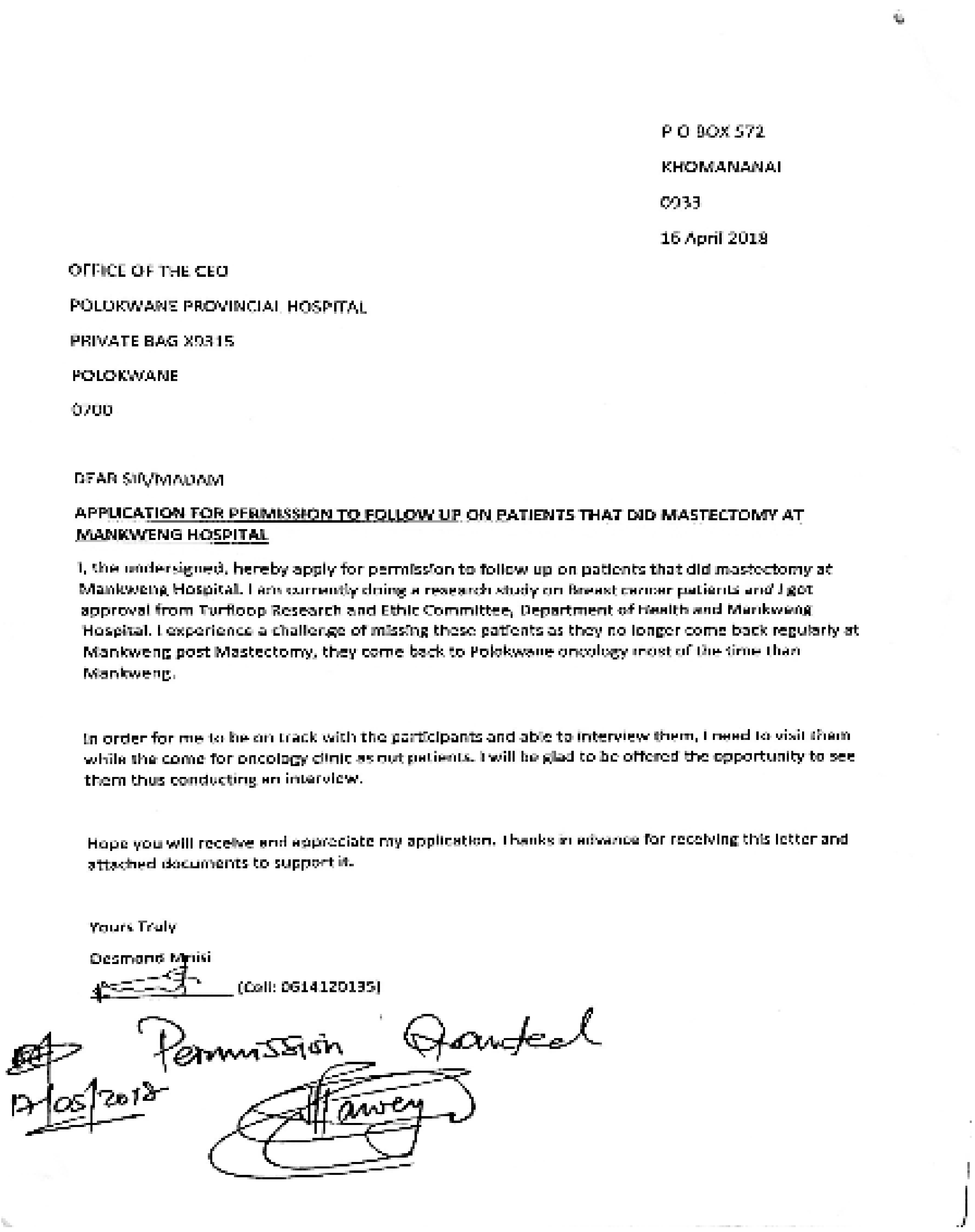
Thanking you in advance

....
Chief Executive Officer

........2018/02/09
Date

DEPARTMENT OF HEALTH
Mankweng Hospital
PRIVATE BAG X1117
SOVENGA 0727
Tel. 015 286 1000
LIMPOPO PROVINCE

ANNEXURE D: PIETERSBURG HOSPITAL PERMISSION



P O BOX 572
KHOMANANAI
0933
16 April 2018

OFFICE OF THE CEO
POLOKWANE PROVINCIAL HOSPITAL
PRIVATE BAG X9315
POLOKWANE
0700

DEAR SIR/MADAM

APPLICATION FOR PERMISSION TO FOLLOW UP ON PATIENTS THAT DID MASTECTOMY AT MANKWENG HOSPITAL

I, the undersigned, hereby apply for permission to follow up on patients that did mastectomy at Mankweng Hospital. I am currently doing a research study on Breast cancer patients and I got approval from Turfloop Research and Ethic Committee, Department of Health and Mankweng Hospital. I experience a challenge of missing these patients as they no longer come back regularly at Mankweng post Mastectomy, they come back to Polokwane oncology most of the time than Mankweng.

In order for me to be on track with the participants and able to interview them, I need to visit them while the come for oncology clinic as out patients. I will be glad to be offered the opportunity to see them thus conducting an interview.

Hope you will receive and appreciate my application. Thanks in advance for receiving this letter and attached documents to support it.

Yours Truly
Desmond Mnisi
(Cell: 0614120135)

Permission Granted
17/05/2018

ANNEXURE E: CONSENT FORM

DEPARTMENT OF NURSING SCIENCE ENGLISH CONSENT FORM

Statement concerning participation in a Clinical Research Project*.

Name of Project / Study: Experiences of women who had undergone mastectomy at Mankweng Hospital, Limpopo Province, South Africa.

I have read the information and heard the aims and objectives of the proposed study and was provided the opportunity to ask questions and given adequate time to rethink the issue. The aim and objectives of the study are sufficiently clear to me. I have not been pressurised to participate in any way.

I know that sound recordings will be taken of me. I am aware that this material may be used in scientific publications which will be electronically available throughout the world. I consent to this provided that my name and hospital number are not revealed.

I understand that participation in this Study / Project is completely voluntary and that I may withdraw from it at any time and without supplying reasons. This will have no influence on the regular treatment that holds for my condition neither will it influence the care that I receive from my regular doctor.

I know that this Study / Project has been approved by the Turfloop Research Ethics Committee (TREC). I am fully aware that the results of this Study / Project will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

The Study/Project envisaged may hold some risk for me that cannot be foreseen at this stage.

Access to the records that pertain to my participation in the study will be restricted to persons directly involved in the research.

Any questions that I may have regarding the research, or related matters, will be

answered by the researcher/s.

If any medical problem is identified at any stage during the research, or when I am averted for participation, such condition will be discussed with me in confidence by a qualified person and/or I will be referred to my doctor.

I indemnify the University of Limpopo and all persons involved with the above

Project from any liability that may arise from my participation in the above project or that may be related to it, for whatever reasons, including negligence on the part of the mentioned persons.

I hereby give consent to participate in this Study / Project.

Signature of researched person: …………………………. Date: ……………………..

Signature of researcher: ………………………………… Date: ………………………..

Signed at: ………………………….this ……………. Day of ……………………2017

Contact No: 061 142 0135

ANNEXURE F: INTERVIEWING GUIDE

English interview guide

Central question:

Could you kindly describe your experiences post Mastectomy operation?

Probing questions:

What are the challenges that you experienced after mastectomy at home, workplace or inside the community?

If challenges were there, how did you manage to cope with such challenges?

Do you still manage to carry out your daily duties just like before?

Did you receive enough support from your family, partner or friends after being diagnosed with cancer even after Mastectomy?

SEPEDI DATA COLLECTION TOOL

Dipotšišo ka Sepedi

Potšišo ya kakaretšo:

Ke kgopela gore a hlalose ka botlalo maitemogelo a gago ka morago ga go dirwa opereišene ya go hlošwa letswele.

Dipotšišo tša go nyaka hlathollo e tseneletšgo:

- Ke kgopela gore o hlološe ditlhlohlo tšeo o itemogelago tšona mabapi le go dirwa opereišene ya go hlošwa letswele ka lapeng, mošomong le mo setshabeng.
- Ge ditlhohlo di le gona o kgona bjang go di laola?
- A o kgona go šoma mešomo ya tšatši le tšatši go swana le mehleng naa?
- A o hwetša thekgo e lekanego go tšwa go balapa, molekane ka morago ga go dirwa opereišene ya go hlošwa letswele?

Swivutiso hi Xitsonga

Swivutiso swa Nkatsakanyo

Ni kombela u hlamusela ntokoto lowu u ngava na wona endzaku ka ku endliwa vuhandzuri bya ku susa mavele?

Swivutiso swa nseketelo

Hi yini mitlhotlho leyi u nga hlangana na yona endzaku ka ku endliwa vuhandzuri bya ku susiwa mavele ekaya, etirhweni na ndhawini leyi u tshamaka ka yona?

Loko ku vile na mitlhotlho, u tirhise yini ku amukela no hlula mitlhotlho leyi?

Wa ha swikota ku endla mintirho ya masiku hinkwawo ku fana na khale xana?

Xana u kumile nseketelo eka va dyangu, murhandiwa wa wena xikan'we na vanghana endzaku ka kuva na fhukuzani na ku endliwa vuhandzuri?

Mbudziso nga Tshivenda

Mbudziso nyangaredzi

Talutshedzani tshenzhemo yanu nga murahu ha u itwa muaro wa damu?

Mbudziso tsengulusi

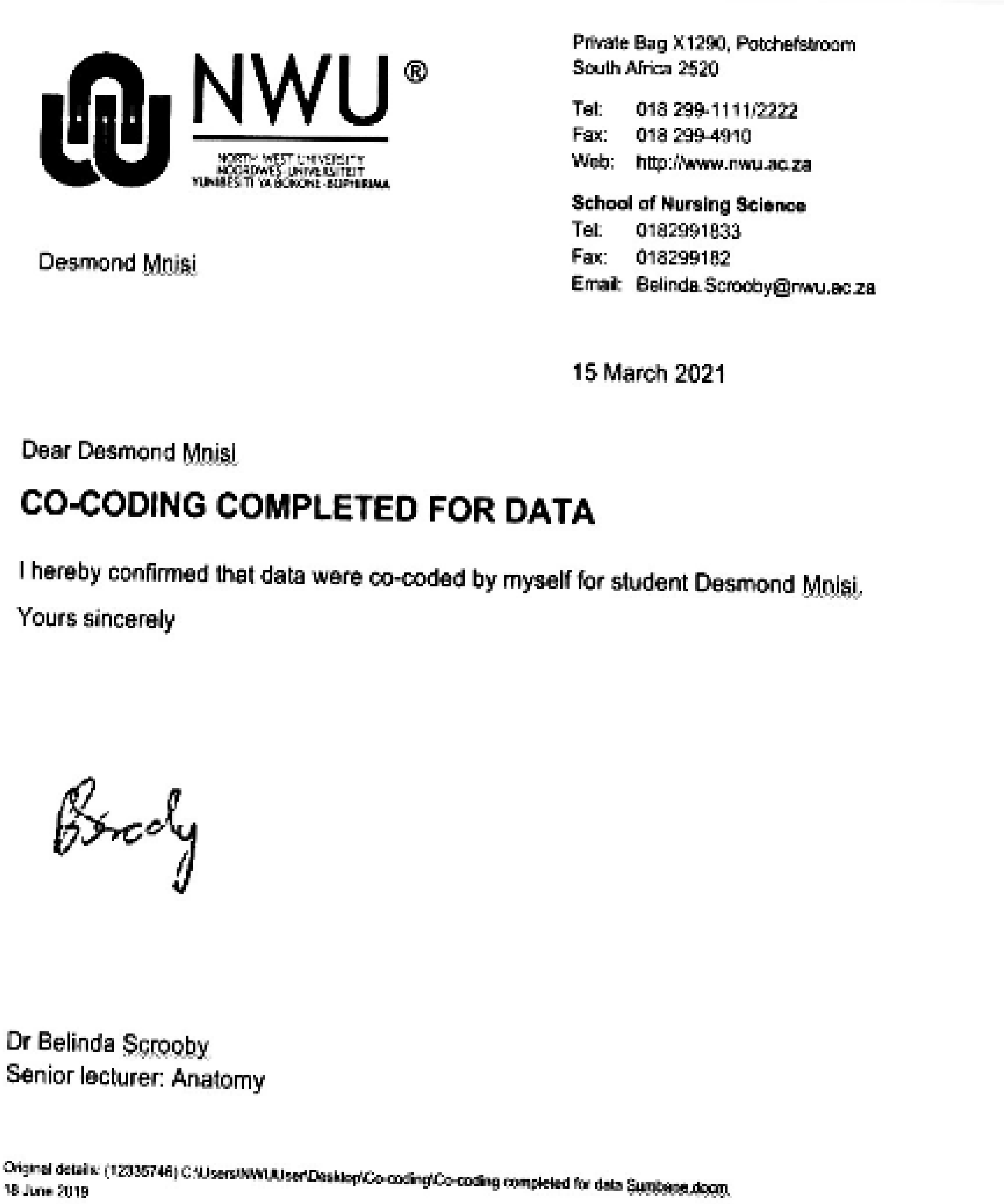
Ndi dzifhoo kaedu dze na tangana nadzo nga murahu ha u itwa muaro,ro lavhelesa hayani,mushomoni kana hune na dzula hone?

Arali khaedu dzo vha one,no kona hani u livhana na dzo kana u tshila nadzo?

Ni kha di kona u shuma mishumo yanu ya duvha nga duva sa zwila kale ni saathu u itwa muaro?

No kona u wana thsikhedzo I fushaho u bva kha muta, mufarisi kana dzikhonani nga murahu ha u itwa ndingo dze dza sumbetsa uri ni na pfuko ya damu, na nga murahuha u itwa muaro?

ANNEXURE G: CO CORDING CERTIFICATE



NWU®
NORTH WEST UNIVERSITY
NOORDWES UNIVERSITEIT
YUNIBESITI YA BOKONE-BOPHIRIMA

Private Bag X1290, Potchefstroom
South Africa 2520

Tel: 018 299-1111/2222
Fax: 018 299-4910
Web: http://www.nwu.ac.za

School of Nursing Science
Tel: 0182991833
Fax: 018299182
Email: Belinda.Scrooby@nwu.ac.za

Desmond Mnisi

15 March 2021

Dear Desmond Mnisi

CO-CODING COMPLETED FOR DATA

I hereby confirmed that data were co-coded by myself for student Desmond Mnisi.

Yours sincerely

Dr Belinda Scrooby
Senior lecturer: Anatomy

Original details: (12335746) C:\Users\NWUUser\Desktop\Co-coding\Co-coding completed for data Sumbase.docm
18 June 2019

ANNEXURE H: EDITING CERTIFICATE

N J Nel
PO Box 365,
BENDOR PARK
0713

Tel: 0741849600

CERTIFICATE

This serves to certify that I have language edited the Dissertation of

Mr DESMOND MNISI

Student number: **201001693**

entitled:

"EXPERIENCES OF PATIENTS WHO HAD UNDERGONE MASTECTOMY AT MANKWENG HOSPITAL IN LIMPOPO PROVINCE, SOUTH AFRICA."

N J Nel

Lecturer of English, Department Applied Languages
Tshwane University of Technology
(Retired)

6 April 2021

ANNEXURE I: TRANSCRIPT

PARTICPANT NUMBER 6

Interviewer-intvr

Respondent-Resp

Intvr: Greetings.

Resp: Greeting to you as well.

Intvr: How are you?

Resp: Fine and how are you?

Intvr: Fine. My name is Desmond Mnisi, I am from University of Limpopo doing research on breast cancer. My topic is the experiences of women who have undergone mastectomy at Mankweng Hospital, in Limpopo Province of South Africa. Here we would like to investigate the challenges from women who had their breast removed due to breast cancer. So I would ask for a permission to do an interview with you before I continue. If you permit me, I will give you a consent form to read and, I will also read its contents for you to sign together with me. This will serve as a proof that you have allowed me to go ahead with the interview. (Participants reading the consent form written in her own language), so do you permit me?

Resp: This permission is the permission as I signed these consent form.

Intvr: This permission is the indication that you have voluntarily given me permission, so you permit me?

Resp: Yes, I do not have any problem.

Intvr: This is the form and on this it is written that I will record the interview, then the recording will be transcribed and be published so that people would be able to read and be informed that there is this kind of challenge so they could get answers to problems and also be able to a better and positive life.

Resp: Hmmm

Intvr: Those who read it would also be able to do other studies similar to this one in order to solve similar problems, and I am permitted by the University of Limpopo Ethical Research Committee to carry on this study.

Resp: Hmmm.

Intvr: I am going to publish the study, your privacy shall also be protected, and you will never hear any one saying that madam whoever has done this and that. I would also not disclose this information and your names to any unauthorised studies. I do not want you name to be known.

Resp: Hmmm

Intvr: In the midst of the interview you could ask any question if you feel like and if you happened to mention some of the diseases that you have never be treated for before I would refer you to the relevant doctor dealing specially with such sickness. Do you allow me?

Resp: Yes

Intvr: If you give me a permission then I will give you this form so that you sign and you shall write the date as well, sign up there and write the today's date here.

Resp: I sign my name?

Intvr: Hmmm, eh, let's start with district, from which district are you coming from, Sekhukhune, Capricorn, and Vhembe?

Resp: I am from Ga-Mothapo,

Intvr: Oh you are from Ga-Mothapo?

Resp: Is not far from Turfloop.

Intvr: Oh, you are from Capricorn?

Resp: Yes.

Intvr: What is your date of your birth?

Resp: Nineteen seventy one.

Intvr: In which date?

Resp: Twenty five September.

Intvr: How many years do you have?

Resp: Forty seven.

Intvr: Forty seven?

Resp: Yes.

Intvr: Hmmm, when did you become aware that you have breast cancer?

Resp: Eish, I was just relaxed, with my one cousin of mine, just relaxed. Then started to feel something on my breast.

Resp: Or let me say I was just busy washing when I felt it more.

Resp: I think it was after the passing of my husband which was in 2016.

Resp: 2017 was the year I started noticing the lump on my breast while washing and I told my cousin.

Resp: She then said '' let me see'.

Resp: I showed her, then she said we must go the clinic, then we agreed that we will go the following day, then following day we went to the clinic.

Intvr: Hmmm.

Resp: Our clinic is Phuti at Ga-Mothapo.

Intvr: Phuti clinic is the one just next to, that site.

Resp: Yes, when we arrived at Phuti I explained to them that I have this kind of a problem, and the nurse only palpitated, then they wrote me a referral letter to Mankweng.

Intvr: Hmmm.

Resp: Yes, then after having written the referral letter I started to go for check-ups in Mankweng. I started to do mammogram and they put me in various machines.

Intvr: Hmmm.

Resp: I took several visits to Mankweng.

Intvr: Hmmm.

Resp: Yes, they checked me, until they pressed me here.

Intvr: Hmmm.

Resp: On the breast. Then the doctor pressed me on the breast, and asked me if there was any relative of mine who had cancer? I said yes.

Resp: The late, my twin sister passed away as a result of cancer. She had a cancer on her leg and another cousin from my maternal family had a breast cancer. She is going for check-ups because of breast cancer, but she is still alive.

Intvr: Hmmm.

Reps: The twin sister unfortunately passed on,

Intvr: Hmmm.

Resp: Yes, then they informed me that the results indicate that you have a breast cancer .They then further said that my breast is too small and as a result they would remove the whole breast instead of the lump only.

Intvr: Hmmm.

Resp: Then I told them that everything they said I agree with me, as long as you could help me; we agreed with each other and then I signed the papers.

Intvr: Hmmm.

Resp: Then they booked me a date for operation and I was operated in July in Mankweng.

Intvr: Okay.

Resp: Yes.

Intvr: After you were operated and lying on your hospital bed, how did you feel?

Resp: I was feeling pain, but maybe because I was stitched.

Intvr: Hmmm, when were you operated on?

Resp: In July last year.

Resp: They were coming to inject us urging the night, and give us painkillers until I was discharged, then went home.

Intvr: Hmmm.

Resp: I was just coming for check-ups, until they removed, I was stitched with?

Intvr: Some staples?

Resp: Yes, until they remove those staples.

Intvr: Hmmm.

Resp: Yes, then I started to feel better.

Intvr: Okay.

Resp: Yes, until today when I started to, they wrote me letter that I should start going to Pietersburg hospital. It implied that those things did not fully disappear in Mankweng. Meaning that I should go for chemos. I then started to come here in Polokwane for chemos.

Intvr: Hmmm.

Resp: I visited chemo sessions for six months.

Intvr: Hmmm

Resp: Yes, then I finished the chemo’s sessions in February.

Intvr: Hmmm.

Resp: Yes, his year.

Intvr: Hmmm okay.

Resp: Yes.

Intvr: Hmmm.

Resp: Then currently I just go for follow-ups, then in September they told me that I am booked, to say I would be visiting the radiation department.

Intvr: Hmmm.

Resp: To go and radiate the breast side.

Intvr: Hmmm.

Resp: They said they are going to radiation here (pointing on the mastectomy area).

Intvr: Hmmm.

Resp: On the 3rd of September they are going to radiate here (Pointing again).

Intvr: On the 3rd September?

Resp: Yes 3rd September, Starting from the 3rd.

Resp: Yes.

Intvr: So, when you're at home looking in the mirror maybe you want to wash or dress bra …

Resp: Hmmm (voice very low).

Intvr: How do you feel as you are currently left with a single breast as you are used to have both of them?

Resp. Eish it is very painful.

Intvr: Hmmm.

Resp: Yes, what shall one say because …. (With faint voice).

Intvr: How did you manage to cope?

Resp: But, I did understood that I am not alone and it is a sickness that has come, and I want to save my life, I could have refused maybe I would not be alive. I decided to agree on what it was said I should do, if I refused I could have been dead, it is like this ARV tablets, if one test and be informed that one is either HIV positive or positive, would be forced to accept you see?

Intvr: Hmmm.

Resp: One just has to accept.

Intvr: Hmmm.

Resp: Yes.

Intvr: Ok, so currently when you wear bra, does it fit.

Resp: I wear this bra with sponges like material.

Intvr: Hmmm, you do not have that official breast?

Resp: No.

Intvr: You never heard about it?

Resp: Never.

Intvr: Ok, at the place where you go for check-ups, you must explain to the doctor, they will measure you and give you an application forms.

Resp: Hmmm.

Intvr: So, when you wear bra you put it on.

Resp: It's just only this one.

Intvr: Hmmm.

Resp: It is just a bra.

Intvr: Mm, right there you just ask, then they will help you?

Resp: Hmmm.

Intvr: So, what did you insert?

Resp: It is just a bra only.

Intvr: Hmmm.

Resp: You could see it is not the same size as the other one?

Intvr: Hmmm.

Resp: I ask from the doctor

Intvr: Yes.

Resp: Okay.

Intvr: Hmmm.

Resp: All right.

Intvr: Hmmm, what is the other thing you want to say or challenges that you came across after you have removed the breast?

Resp: I did not encounter any challenge so far.

Intvr: Are you working?

Resp: No I am not working

Interv: The domestic duties at home including cleaning, cooking etc. Were you able to perform them?

Resp: I did them.

Interv: I mean after you have removed the breast were you doing them, you did not have any problem doing those duties?

Resp: Yes.

Intvr: So do they support you at home and do you have life partner?

Intvr: I live with my children, the first one graduated. I do not remember when was his graduation from University of Limpopo, and the other two boys.

Resp: The older one still searching for a job, and he was born in 1991.

Resp: As I told you that my husband passed on.

Intvr: Okay.

Resp: So, I am left with three boys. The other one in grade 11 and another in grade 5.

Intvr: Do they give you support at home?

Resp: They really support me, I am left with the mother in-law, the brother and sisters in law and my father's brother. They really supported me, I do not want to bad-mouth them.

Intvr: Hmmm.

Resp: Yes.

Intvr: Hmmm.

Resp: Yes.

Intvr: What is it that you think the government should do in order to assist people of your nature, what do you think government could do; ok, do you support yourself financially?

Resp: I did, I around February.

Intvr: Hmmm.

Resp: Yes, in February, I asked the doctor and explained my problem to the doctor that I am not employed. I explained to him my situation that he could not apply Social disability grand on my behalf?

Intvr: Hmmm.

Resp: He then completed a form for me for SASSA and I took it to the SASSA where I was assisted.

Intvr: Hmmm.

Resp: The money was paid in due course. They then told me when I should come and renew the application.

Intvr: Hmmm.

Resp: Yes.

Intvr: Okay.

Resp: Yes, that is how I got assisted.

Intvr: Hmmm.

Resp: Seeing that the transport is costly when going to and from, because currently it cost R50.00 return fare.

Resp: So, if one does not work and is without income, it become a problem, do you see?

Intvr: So, you want to be helped with social grant?

Resp: Yes,

Intvr: Ok, is there anything that is still an issue as a result of this sickness that you want the government to step in for?

Resp: Eish, help me guide me, maybe I need to be assisted?

Intvr: What helped you so you could cope, who motivated you to accept you situation?

Resp: I was motivated by my cousin, who is my brother's sister, also who is going for check-ups in Johannesburg.

Intvr: She had cancer as well.

Resp: Yes, but hers was not yet removed by that time.

Intvr: Hmmm.

Resp: Yes, she was the one who was comforting me. She was consulting in Pretoria too for breast cancer, and she also comforted me after my husband's death, and said that I should not worry.

Intvr: Hmmm.

Resp: Yes.

Intvr: Hmmm, here, at home or in the province is there any support group whereby women whose breast is removed sit together and talk about their conditions?

Res: At home where I staying?

Intvr: Or here at the province?

Resp: No. no.

Intvr: If it can be formed, do you think it will help?

Resp: Yes, It could help.

Intvr: Okay.

Resp: Hmmm, it could help.

Intvr: Okay, I thank you for your time and patience, I am done with our interview.

Resp: Yes.

Intvr: I thank you for your cooperation.

Resp: I thank you too.