

**Exploring Experiences of Individuals with Breast Cancer  
Post-Mastectomy at Kenyatta National Hospital: A  
Phenomenological Study**

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**A research project submitted in partial fulfillment of the  
requirements for the conferment of the Degree of Master of Science  
in Nursing (Oncology Nursing) of the University of Nairobi**

**NOVEMBER, 2023**

## DECLARATION

I, Mary Akinyi Owino, declare that this research project is my original work and has not been presented for any examination in any other institution.

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## **DEDICATION**

I dedicate this research project to my special beloved family, dear husband Joe and all our beloved children, Gillian and Mureithi, Irene and Sammy, Louise and Kevin, Eva, Evelyn and David, Gloria and Ben. This work is also dedicated to my grandchildren Sifa, Ivanna, Amara, Eden, Marion, Esther, Tugi and Asher. I am most grateful to you all.

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## **LIST OF ABBREVIATIONS**

BC	Breast Cancer
BI	Body Image
BSC	Breast Cancer Survivor
BRS	Breast Reconstructive surgery
CTC	Cancer Treatment Centre
KNH	Kenyatta National Hospital
QOL	Quality of life

## **OPERATIONAL DEFINITIONS**

**Body image** - Body image can be described as the patient's feelings and attitudes toward their body which develop as a result of cancer diagnosis and treatment, this may be positive or negative depending on the interventions taken to improve the body image.

**Breast cancer** - Is a description of malignant growth in a person's breast which is confirmed by histology report.

**Breast reconstructive surgery** - Is an elective restorative surgery involving the use of an implant or autologous tissue or a combination of the two methods which can be done immediately after mastectomy or as a delayed surgery.

**Cancer care** - Refers to services accorded to a patient with breast cancer. These services include treatment modalities, palliative care, psychosocial counselling, and investigations like radiography and laboratory among others.

**Coping mechanism** - These are strategies developed by individuals in the face of a stressful event or support through counselling to help the individual manage painful or difficult emotions.

**Mastectomy** - Is a surgical procedure involving the removal of all or part of the breast, classified into partial, simple, modified-radical, and radical. In this study, mastectomy is referred to from day one after surgery.

**Patient experience** - Encompasses the range of interactions that patients have with the healthcare system including their care from health plans and from doctors, nurses and staff in hospitals, physician practices, and other health care facilities. The patient experience includes. Several aspects of healthcare deliveries that they value highly when they seek and receive care, such as getting timely appointments, easy access to healthcare and good communication with health care providers.

**Psychological** - Is related to the mental or emotional state of a patient diagnosed with breast cancer who is undergoing several treatment modalities including mastectomy.

**Quality of care** - From the patient's perspective can be defined as the totality of features and characteristics of a health care product or service that bear on its ability to satisfy the stated or implied needs of the consumers of these products.

**The cancer treatment center** - Is a unit which offers its service to patients with cancer. The services include review of new patients and referrals, chemotherapy, admissions, review of patients with results, marking for radiotherapy, out-patient chemotherapy, nuclear patients review, follow-up of patients, joint radiotherapy, ear nose and throat clinic, and emergency radiotherapy.

## ABSTRACT

**Background:** Worldwide, breast cancer (BC) is the most prevalent malignancy affecting women and ranks as the second most fatal form of cancer. When detected early in stages i and ii, mastectomy is the most prevalent and efficacious surgical intervention for breast cancer. Nevertheless, post-mastectomy body image changes may negatively impact the psychological, physiological, sex-related and social well-being of affected women.

**Objective:** This study explored the experiences and perspectives of individuals with breast cancer post-mastectomy at Kenyatta National Hospital.

**Methods:** A cross-sectional qualitative survey was undertaken. The constructivism paradigm was adopted. Adult patients with breast cancer post mastectomy attending clinics or admitted at Cancer Treatment Center (CTC) in KNH were targeted as respondents. A study sample of 10 patients was purposively interviewed on the basis of the principle of data saturation. In-depth interviews using an interview guide were carried out among the study participants. Audio-recording was done using SONY ICD PX 333, data transcribed verbatim with the data analysed using thematic content analysis using NVivo v.11 Software. The study was approved by both the KNH-UoN Ethics and Research Committee and KNH management.

**Results:** The study participants were females most of whom had visited KNH for treatment. In relation to the participant's physiological experiences and perspectives post-mastectomy, diminished physical strength/functioning emerged as the main theme with altered body image, disrupted work life and disrupted sexual life as it's sub-themes. In relation to the participant's psychological experiences and perspectives post-mastectomy, mental distress emerged as the main theme with anxiety and stress, hopelessness in life and low self-esteem as it's sub-themes. In relation to the participant's sociological experiences and perspectives post-mastectomy, social support emerged as the main theme with family support and social life as it's sub-themes. In relation to rehabilitation support systems available to persons with breast cancer post-mastectomy, psychosocial support programs emerged as the main theme with counselling, group therapy and breast reconstructive surgery as it's sub-themes.

**Conclusions:** The quality of life of individuals with breast cancer post mastectomy is affected in three dimensions; physiologically by reduced physical strength disrupting their normal work and sexual life; psychologically by having mental distress, anxiety and low self-esteem which may require continuous counselling to regain mental stability; sociologically by having disruptions of social and family life keeping them isolated from normal functions.

**Recommendations:** Health practitioners at KNH's Cancer Treatment Centre could ensure that individuals with breast cancer post mastectomy seen in the hospital go through a structured evaluation of physiological, psychological and sociological needs for execution of holistic care.



## **1.0: CHAPTER ONE: INTRODUCTION**

### **1.1 Background information**

Breast cancer ranks as the second most prevalent cancer among women worldwide and the most prevalent cancer in women as a whole. According to the latest global cancer burden statistics, the incidence of breast cancer amounted to 2.3 million incident cases in 2020. Furthermore, among women worldwide, this disease remains the primary cause of cancer-related mortality (Siegel et al., 2021; Kang et al., 2021; Lei et al., 2021; Prat et al., 2013). Research conducted in sub-Saharan Africa (Bray et al., 2022; Sung et al., 2021) documented 186,598 cases of breast cancer and 85,787 deaths associated with the disease.

Mastectomy is the prevailing surgical approach for breast cancer, as recommended by cancer therapy regulations. Breast reconstructive surgery (BRS) is contingent upon the seriousness of the case and the patient and surgeon's agreement (NCCN, 2021). It is regarded as the most efficacious method of cancer treatment, with approximately 40% of breast cancer patients worldwide undergoing mastectomy each year (Sasada et al., 2021). However, following mastectomy, women may experience a transformation in their reality. A mastectomy is a medical intervention in which a portion or the entirety of the breast is removed. It can be categorized as radical, simple, modified-radical, or partial (Goethals et al., 2019). Research has demonstrated that breast surgery, irrespective of whether it is a lumpectomy or mastectomy, significantly impacts an individual's social and psychological life and well-being. Specifically, it affects the patient's sense of womanhood, body image, and, to a lesser extent, her behaviour and social integration. The effects of breast surgery become particularly evident in the physical appearance of the patient throughout the initial three to twelve months following the procedure (Postolică et al., 2019; Soleimani et al., 2022).

This study employs the notion of body image proposed by Baskin et al. (2021) to examine the emotional and cognitive transformations that occur in patients following a cancer diagnosis and subsequent treatment. Maleki et al. (2021) found that among 765,487 women worldwide who were diagnosed with small, unilateral breast cancer, 31% underwent mastectomy. The majority of these women stated having body image

disturbances, including diminished self-esteem, feelings of femininity loss, reduced sexual activities, anxiety, loneliness, depressive symptoms, guilt and shame, nervousness about recurring, and worry of dying.

According to research by Findlay-Shirras et al. (2021), the incidence of mastectomy grew more than six fold (from 4% to 25%) in western nations, including Canada and the United States, among all age groups between the ages of 70 and 23. Annually, more than one hundred thousand American women undergo radical mastectomy, with more than fifty percent opting for immediate breast reconstruction (Rosenkranz et al., 2021). Mastectomy incidences in the United Kingdom continue to hover around 35% (range: 23%–64%) (Asselain et al., 2018). In contrast, between July 2010 and March 2017, 364,047 patients in Japan underwent mastectomy for stages 0–III breast cancer (Konishi et al., 2021). Breast cancer is the most prevalent form of malignancy among women in China's mainland. Around eighteen percent of newly diagnosed breast cancer cases in China occur in Western counties. In China, the utilisation of mastectomy is considerably higher than in Western countries, with over 80% of Chinese breast cancer survivors (BCS) having undergone the procedure. A significant proportion of the survivors expressed apprehension regarding the loss of femininity resulting from the breast removal (Liu et al., 2022). Fallbjork et al. (2019) found that in Sweden, approximately 45% of women diagnosed with breast cancer undergo mastectomy; the vast majority of these women report a reduction in sexual attractiveness and comfort levels when having a sexual encounter.

The information available regarding the difficulties associated with cancer of the breast handling in Africa, as well as efforts to enhance outcomes, is insufficient (Amouzou et al., 2022; Sharma et al., 2022). For the majority of sub-Saharan African nations, the five-year overall survival rate for breast cancer patients does not surpass 60% (Twahir et al., 2021). According to data provided by the World Health Organisation, the mortality rate among African women who have been diagnosed with breast cancer exceeds fifty percent (Vanderpuye et al., 2017). Despite the progress made in recent decades, specific attributes persist throughout the African continent. These include inadequate access to cancer drugs, a scarcity of oncology specialists, restricted availability of fundamental and contemporary systemic and hormonal therapies for breast conservation, adherence to detrimental socio-cultural practices,

and inadequate availability of drugs for cancer (Amouzou et al., 2022). The observed disparity in survival rates between women diagnosed with breast cancer in Africa and nations with higher incomes is substantially influenced by these factors (Sharma et al., 2022).

In Africa, surgical intervention is the primary mode of treatment for breast cancer. Even though South and North Africa are better resourced to tackle the burden of breast cancer, surgery, in the form of mastectomy, represents the most popular option in all African countries and particularly in most of the sub-Saharan Africa (Sutter et al., 2021). The rates of mastectomy vary greatly across the different countries in Africa, with the majority of countries reporting mastectomy rates of well above 50%, with a considerable number reporting rates of even above 90%. The average mastectomy rate in Africa is approximately 85%. In Niger, 90% of breast cancer patients presenting with advanced disease were treated with mastectomy, according to Soleimani et al. (2022). In a similar vein, data from Tanzania, Eritrea, and Rwanda suggests that mastectomy is performed on as many as 99 percent of breast cancer patients for a variety of reasons, including the disease's advanced stage and the absence of alternative treatment options. Other countries in which mastectomy rates are applied in over 90% of the patients with breast cancer include Cameroon, Malawi, Zambia, Mali and Congo Brazzaville (Bray et al., 2022; Sutter et al., 2021). Countries such as Kenya, Uganda, Sudan, Ghana, Angola, Namibia and Zimbabwe reports mastectomy rates of between 60% and slightly under 90% (Twahir et al., 2021). However, slightly lower rates of mastectomies are seen in countries including South Africa, Egypt, Nigeria and Morocco which have been attributed to availability of other complimentary adjuvant therapies in these countries (Bray et al., 2022; Sharma et al., 2022). This divergence in mastectomy rates in African countries seems to be dependent on both patient preference and country-specific resources and suggests possible differences in breast cancer care approaches among African countries (Amouzou et al., 2022).

According to an investigation (Thakur et al., 2022), the incidence of body image disturbances among breast cancer patients in India who underwent a mastectomy and reported experiencing psychological distress, ranging from 31% to 67%, is substantial. Such disturbances are also associated with anxiety and depressive

symptoms. A distinct investigation (Shanmugakrishnan et al., 2021) reveals that subsequent to mastectomy, depression was reported as 77.5% of patients in India, with 76.5% expressing a preference for breast reconstruction. A research investigation conducted in Ghana by Anim-Sampong et al. (2021) unveiled that individuals who underwent mastectomy experienced detrimental psychological and emotional consequences. With regard to their mastectomy experiences, 56.7 percent of respondents agreed that they felt less feminine, 71% reported psychological distress, and 63.3 percent reported a loss of self-confidence. Regardless of socioeconomic standing and age, the majority of women opted for breast reconstruction following mastectomy but even after undergoing reconstruction they still experience psychosocial effects or body image disturbances that may persist for years, affecting their quality of life (Ceithaml, 2021).

Breast cancer is the leading malignancy diagnosed in Kenya and the leading cause of cancer-related mortality among women, according to country statistics. The annual incidence of new cases of breast cancer (BC) among women is estimated to be 6,799 in 2020, up from 5,985 in 2018 (Sung et al., 2021). Additionally, research suggests that the annual death toll from BC in Kenya is approximately 2,550 and is estimated to be around 6,000 a projected 35% increase is anticipated by 2025 (Ferlay et al., 2021). Mastectomy represents the prevailing surgical intervention for breast cancer.

In Kenyatta National Hospital, 90 mastectomies were done in 2021 despite the impact of Covid-19 (KNH CTC registry) as compared to other previous years before the impact of Covid-19 which recorded slightly lower numbers ranging between 64 to 82 cases yearly for the last 5 years (KNH CTC registry) indicating a constant increase in new cases.

The social, emotional, and psychological health of breast cancer patients is impacted by mastectomy. In this regard, nurses assume vital responsibilities in comprehending and providing assistance to patients in their physical, social, and even sexual lives subsequent to the procedure. Patients require education both prior to and following mastectomy in order to adapt to their new circumstances and embrace treatment procedures. This study has the potential to serve as a benchmark that guides the

development and evaluation of optimal implementation strategies to guarantee high-quality care for patients undergoing post-mastectomy management.

In Kenya, mastectomy is the most common surgical treatment for breast cancer. In Kenyatta National Hospital, 90 mastectomies were conducted in 2021 despite the impact of Covid-19 (KNH CTC registry, 2022) as compared to other previous years before the impact of Covid-19 which recorded slightly lower numbers ranging between 64 to 82 cases yearly for the last 5 years (KNH CTC registry, 2019) indicating a constant increase in cases each year. From a psychological standpoint, mastectomy is one of the most debilitating procedures; it has a greater impact on body image, self-esteem, and femininity than cancer itself (Iddrisu et al., 2020; Padmalatha et al., 2021a; Kocan et al., 2016). Mastectomy can be a challenging procedure for women due to the vitality of the breast and the potential physical, sexual, and emotional repercussions that may befall who have been diagnosed with breast cancer. One year following mastectomy, one in four women with breast cancer were estimated to have depressive symptoms (Grujic et al., 2021; Padmalatha et al., 2021b).

According to a study conducted in Ghana (Anim-Sampong et al., 2021), individuals who underwent mastectomy experienced negative psychological and emotional consequences. With regard to their mastectomy experiences, 56.7 percent of respondents agreed that they felt less feminine, 71% reported psychological distress, and 63.3 percent reported an erosion of confidence in themselves. Shanmugakrishnan et al. (2021) found in a different investigation that 76.5% of patients in India who had undergone mastectomy reported developing depression, and 76.5% said they would prefer breast reconstruction. According to a study by Baskin et al. (2021), among 765,487 women worldwide who were diagnosed with small, unidirectional cancers of the breast, 31% went through mastectomy. Most of these women reported experiencing body image disturbances such as diminished self-esteem, feelings of femininity loss, reduced romantic activities, anxiousness, loneliness, depression, humiliation and prejudice, guilt, anxiety about possible recurrence, and dread of losing their lives (Maleki et al., 2021).

## **1.2 Statement of the problem**

Mastectomy causes greater disfigurement than other forms of surgery leading to greater poorer physical outlook and worsening standard of living. Particularly debilitating to body image are the alterations and removing of all the breast causing asymmetry and changed appearance physically with an adverse impact on the body image, especially on women with very high expectations of physical beauty (Türk et al., 2018). Most African cultures consider women as the pillars of families and the community, they are the careers and keepers of their families, because of many biopsychosocial challenges that requires multidisciplinary medical and surgical interventions, they lose their social identity in role-playing which might keep them in social isolation (Anim-Sampong et al., 2021)

Breast cancer and its associated therapies have extensive implications for the psychological and sexual well-being of women, primarily attributable to the individual's impression of a changed body or body image (BI). If left untreated, these modifications in body image have the potential to heighten the susceptibility to depression and mood disorders, as well as hinder romantic interactions with others, potentially leading to discord within a marriage. The significance of breasts in relation to the societal role of women is frequently disregarded by the majority of individuals, which includes medical professionals.

Healthcare environments, including the Kenyatta National Hospital Cancer Treatment Centre, prioritize physical recovery and caregiving above all else. As a result, concerns related to gender identity and status are relegated to a secondary position. Gaining insight into the ramifications of mastectomy on the interpersonal interactions and interconnectedness of patients would empower healthcare professionals to facilitate the transition process for women and consider implementation of psychosocial and surgical rehabilitation interventions available to improve the quality of their care and livelihood.

## **1.3 Justification of the study**

Mastectomy is the most common surgical treatment for breast cancer and patients have raised psychosocial concerns that have not been incorporated into their plan of

management (Lundberg et al., 2022). The majority of women managed for breast cancer in many settings across the globe are relatively young, many in their forties and most of them may be unprepared for the physical, sexual, and psychosocial outcomes of mastectomy, therefore, interfering with the quality of life and overall accomplishment (Sutter et al., 2021; Twahir et al., 2021). Understanding these concerns may help address the fears of women who refuse treatment and aid in the care of those who have had a mastectomy (Thakur et al., 2022). The current study offers insights into the experiences of body image of individuals with breast cancer post-mastectomy in several dimensions, key areas being, physical, psychological which includes mental and sexual, social and lastly psychosocial support and breast reconstructive surgery which gives the woman a feeling of wholeness improving the body image and restoring self-confidence.

#### **1.4 Research questions**

- i. What are the physiological experiences and perspectives of individuals with breast cancer who have undergone mastectomy at Kenyatta National Hospital?
- ii. What are the psychological experiences and perspectives of individuals with breast cancer who have undergone mastectomy at Kenyatta National Hospital?
- iii. What are the sociological experiences and perspectives of individuals with breast cancer who have undergone mastectomy at Kenyatta National Hospital?
- iv. What are the rehabilitation support systems available to individuals with breast cancer post-mastectomy at Kenyatta National Hospital?

#### **1.5 Research objectives**

##### **1.5.1 Broad objective**

To explore experiences and perspectives of individuals with breast cancer post-mastectomy at Kenyatta National Hospital.

##### **1.5.1 Specific objectives**

- i. To explore physiological experiences and perspectives of individuals with breast cancer who have undergone mastectomy at Kenyatta National Hospital.

- ii. To explore psychological experiences and perspectives of individuals with breast cancer who have undergone mastectomy at Kenyatta National Hospital.
- iii. To explore sociological experiences and perspectives of individuals with breast cancer who have undergone mastectomy at Kenyatta National Hospital.
- iv. To describe rehabilitation support systems available to individuals with breast cancer post-mastectomy at Kenyatta National Hospital.

### **1.6 Significance of the study**

The investigation's outcomes indicate that mastectomy and breast cancer have adverse effects on a woman's body image. The experiences of patients are highlighted, with an emphasis on the physical, psychological, and social trauma and loss that is associated with negative body image. The results address current deficiencies in the literature regarding the treatment of individuals diagnosed with breast cancer and serve as a foundation for the formulation of workable approaches that would enhance the standard of care delivered to such patients at Kenyatta National Hospital.

The implication of surgical operation of the breast on one's self-appreciation and psychological wellness calls for nurses to take necessary steps for identifying and referring patients for counselling to prevent psychological disorders that may occur. The present investigation offers a comprehensive examination of the post-mastectomy experiences of patients, taking into consideration the variations in their impressions of relations across cultures. The outcomes of this qualitative and descriptive investigation are anticipated to make a valuable contribution towards the development and enhancement of body image-related supporting therapy for post-mastectomy women at KNH.



## **2.0: CHAPTER TWO: LITERATURE REVIEW**

### **2.1 Introduction**

This section provides a look at pertinent publications relating to the experiences of physical outlook alongside the health impact as well as potential involvements on individuals with breast cancer post-mastectomy, a phenomenological, qualitative and descriptive study at Kenyatta National Hospital. In order to determine the knowledge gaps and potential interventions, we explored the literature to find out what other published studies were on equipping caregivers with knowledge and skills for managing patients diagnosed with breast tumor outside the health care settings. This study also made use of research publications drawn from different medical empirical sources such as PubMed, EMBASE, Cochrane Library, PubMed Central, Ebsco Host, and Elsevier. Zotero Desktop was applied in organizing and citing references acquired.

Breast cancer (BC) ranks as the second most prevalent cancer globally and the second leading contributor to mortality among women (Sung et al., 2021). Body image (BI) is a complex construct that encompasses individual's thoughts, actions, attitudes, and views, both positive and negative, regarding their physical appearance and self-perception. It's formation is a fluid process that is impacted not only by an individual's physical and psychological attributes, but also by the socio-cultural environment (Gonzalez et al., 2018). A mastectomy comprises the surgical excision of a portion or the entirety of the breast. It is categorized as radical, simple, modified-radical, or partial (Goethals et al., 2019). It's an important treatment method in breast cancer but on the other hand, mastectomy has a deep negative body image impact in females as it diminishes their self-value and leaves them feeling mutilated therefore threatens perceptions of femininity (Türk et al., 2018). We assessed and evaluated the experiences of body image of individuals with BC post-mastectomy in several dimensions, key areas being, physiological, psychological, sexual, social, and cultural together with psychosocial interventions and lastly breast reconstructive surgery.

## **2.2 Physiological experiences and perspectives of individuals with breast cancer post-mastectomy**

The presence of breast cancer and its subsequent treatment can have profound implications for a woman's overall well-being, including her lifestyle and physical health. Numerous anatomical and physiological problems can result from mastectomy and functionally related lymphatic system components, including lymphedema, weakening of the muscles, immobility of the involved limb, and improper orientations (Li et al., 2022; Zhou et al., 2019). These conditions may induce pain perceptions and hinder the ability to lift objects, leading to restrictions in everyday tasks for those who are younger. Should these difficulties persist, they may face job termination, thereby impacting the financial stability of their families. Furthermore, it was found in an investigation (Mülkoğlu et al., 2022) that patients who developed lymphedema are negatively impacted in terms of both sexual functions and quality of life subsequent to mastectomy. Consequently, healthcare professionals must exert utmost diligence in order to mitigate certain physical adverse effects. This can be achieved through the promotion of physical activity during hospitalization, correct placement of the limb in question, and the maintenance of effective pain management both within the hospital setting and at their homes.

Mastectomy causes greater disfigurement than other forms of surgery leading to much more poor appearance physically and decreased life's standard among affected females. Particularly debilitating to body image (BI) are the alterations and complete removing of all the breast causing asymmetry and changed physiological outlook with an adverse impact on the BI, especially on women with very high expectations of physical beauty (Türk et al., 2018). Studies show that mastectomy may lead to complications like any other surgical procedures,(Yabe et al., 2021) stated that sarcopenia which is a degenerative condition causing muscle wasting and reduced muscle strength hence limitation of arm movement, is an aggravating attribute for skin flap necrosis and might constitute a significant determinant in the preoperative assessment of patients slated to have complete mastectomy, according to the study by (Yabe.,2021) 49% patients post mastectomy present with sarcopenia, which affects the patient's BI greatly.

When considering physical wellness, research has consistently shown that an adverse impression of one's appearance is correlated with increased sexual challenges. These challenges may manifest as dryness in the vagina, hot flashes, atrophic vaginitis, and diminished sexual desire. Premature menopause, a common consequence of chemotherapy and radiotherapy, can significantly impair the sexual well-being of younger women undergoing breast cancer treatment following mastectomy (Paterson et al., 2016). The way in which one perceives their own body outlook has the potential to significantly impact their life's quality. This effect may persist for an extended period of time despite effective treatment. Therefore, it is important for the health care workers to evaluate the physical body changes after mastectomy in order to avert negative biopsychosocial functioning in the patients (Gichuru et al., 2020). The health care professionals should plan to discuss these concerns with the patients advising them on temporary remedies like well-designed prosthesis and breast reconstructive surgery that could be a possible solution to most of these physical and psychological distress due to negative body image (Gichuru et al., 2020), this study recommended that adequate counselling before, during and after surgery is important in order to help the patients adapt to their new medical condition.

### **2.3 Psychological experiences and perspectives of individuals with breast cancer post-mastectomy**

Body image refers to an individual's cognitive perception of their own physical outlook, condition of well-being, optimal functionality, and sexual wellbeing. As stated by Brunet et al. (2021) and Yamani Ardakani et al. (2020), the significance and symbolic value attributed to a woman's breasts are components of her body image. The greater the importance she places on her breasts, the more catastrophic the consequences of a mastectomy may be. It entails the relinquishment of the previous form and damages the perception that women have of their own bodies; it is regarded as an assault on body image that induces feelings of unattractiveness in people (Turk et al., 2018).

The breast in itself is a very important reproductive accessory organ especially to women because it gives them a sense of identity, and physical beauty, and is also important in their sexual life (Zhou et al., 2019). Mastectomy affects the sexual

function of the woman. A research investigation conducted in Sweden by Lundberg et al. (2022) examined the mental ramifications of mastectomy among married women. The findings revealed that a significant proportion of the participants experienced a diminished sense of femininity subsequent to the procedure. Additionally, the women reported challenges in breastfeeding, reduced desirability among their partners, and a negative alteration in their body image. Furthermore, approximately 38% of the women disclosed having divorced or parted from their partners within the three years subsequent to the mastectomy.

According to a separate study (Kocan et al., 2019), the majority of respondents believed that the breast was an organ that exemplified the beauty of women and defined femininity, motherhood, and attraction. The participant's statements demonstrated that the breast is not solely an organ, but also a symbol with multiple connotations; a considerable number of women expressed concern regarding the adverse effects of their physical appearance/image following the surgical breast operation. The framework was characterised by the following adjectives: "dreadful, awful, frightening, unappealing bent and disintegrated." Nevertheless, the predominant criticism regarding their outward appearance revolved around the perception that they were half-formed due to the absence of a breast (Zhou et al., 2020). The participants in an additional study (Cheng et al., 2018) characterised their physical appearances as distorted, damaged, malfunctioning, disproportioned, wounded, and hollow. These are profound indications of mental anguish brought on by a mastectomy's negative impact on body image; for a higher quality of life, psychological therapy and possible surgical correction are required.

Prior research has documented that removing one or both breasts is linked to a variety of negative outcomes, including diminished femininity, fertility, beauty, and sexuality, as well as anxiety regarding the prospect of a recurrence. Additionally, the procedure can induce stress, feelings of embarrassment and shame, and a diminished sense of self-worth, which is known as the "half-woman complex" (Zhou et al., 2020).

Psychologically, mastectomy is one of the most incapacitating procedures; it negatively impacts body image, feelings of worth, and womanhood, and causes more distress than cancer itself. A number of factors impact the quality of life of breast

cancer patients: pain, fatigue, depression, anxiety regarding recurrence, diminished sense of womanhood and elegance, and alterations in body image, self-esteem, and sexuality (Iddrisu et al., 2020). Anxiety episodes and body image disorders may have an impact on sexual quality of life, which is considered one of the foundations of a person's general state of life. These factors typically become apparent following a mastectomy (Archangelic et al., 2019). According to an investigation by Anim-Sampong et al. (2021), the majority of those who participated experienced negative psychological and emotional effects as a result of mastectomy. Specifically, 56.7 percent of respondents indicated that undergoing a mastectomy diminished their sense of femininity, 71% reported experiencing psychological distress, and 63.3 percent reported a loss of self-confidence. Additionally, the research findings indicated that 63.8 percent of the respondents acknowledged modifying their lifestyles subsequent to undergoing a mastectomy. Additionally, 58% of the participants admitted to experiencing social exclusion, and 75% turned to breast prostheses as a means of evading attention.

One in four women with cancer of the breast acquires indications of sadness one year after undergoing a simple or radical mastectomy, according to (Padmalatha et al., 2021b); both procedures were linked with depression in women. A negative body image has been suggested to be correlated with increased psychological distress among individuals diagnosed with breast cancer. Additionally, it has been previously linked to severe depression and a diminished quality of life (QOL). It has been found that the majority of individuals will encounter anxiety, fear, and depression at some point in their lives if they are diagnosed with cancer. Moreover, those who manifest physical symptoms that are linked to the disease are at a greater risk of experiencing emotional distress (Grassi et al., 2019). Davis et al. (2020) discovered that psychological and physical symptoms associated with body image were associated with higher levels of mental and physical anguish among younger women.

Lovelace et al. (2019) noted that women who are up to 2.5 times more likely to suffer from sexual problems after receiving a diagnosis of breast cancer are less pleased with their body appearance; this finding emphasized the need to address both of these issues simultaneously. Restricting the discourse surrounding sexuality subsequent to breast cancer treatment to mere sexual functionality fails to consider psychological

dimensions of sexuality, including body image perceptions. While body image and sexuality are interconnected, they are separate concepts that can have an impact on the breast cancer survivor's quality of life. Sexuality is a fundamental aspect of an individual's holistic well-being; how one views one's body is a critical component of sexual health, as has been established (Davis et al., 2020). Psychological adaptation through counselling is very key to restore their quality of lives.

#### **2.4 Sociological experiences and perspectives of individuals with breast cancer post-mastectomy**

In addition to serving a vital physiological function during critical stages of a woman's life, the breasts are also a cultural emblem of sexuality, sensuality, and femininity. Although mastectomy is performed to treat breast cancer, it disrupts the equilibrium of the "Perfect body" and transforms it into a "imperfect" one; this results in a number of health-related issues pertaining to sexuality, psychology and self-perception (Archangelo et al., 2019).

In addition to other social connections, social support from members of family (particularly friends and partners) is crucial for dealing with and recuperating from cancer of the breast and its treatments. A crucial element in the treatment and management of breast cancer survivors need to be social support (Aprilianto et al., 2021). In support of the treatment of distress among cancer patients, supportive-expressive group psychotherapy and stress reduction programmes are implemented as interventions.

Body Image (BI) transformation has a profoundly adverse effect on the social lives of breast cancer survivors. Participants in a study (Kocan et al., 2019) reported that the loss of a breast negatively impacted their relationships with their spouses, and they were concerned about this. They reached the conclusion that mastectomy has a negative impact on the relationships between spouses and their children. Research has indicated that women who have undergone mastectomy may desire to project a stronger appearance for their children. In an effort to conceal this, some may opt to conceal their loss with brassiere prostheses (Gichuru et al., 2020). Additionally, some

women may choose to avoid social situations due to their appearance following breast loss.

Most African cultures consider women as the pillars of families and the community, they are the careers and keepers of their families, because of many biopsychosocial challenges that requires multidisciplinary medical and surgical interventions, they lose their social identity in role-playing which might keep them in social isolation(Anim-Sampong et al., 2021). Additional research conducted in different nations has similarly documented the prevalent result that mastectomy has an adverse effect on the social lives of women (Kocan et al., 2019). A multitude of alterations that can substantially affect one's quality of life (QOL) may be linked to a negative body image subsequent to cancer treatment. Body image disturbances have the potential to adversely impact a woman's emotional state and interpersonal connections, ultimately resulting in social disgrace and subsequent separation from society (Türk et al., 2018). Psychosocial education is quite important in order to help with adaptation to this new change.

An investigation examining the psychosocial consequences of mastectomy among patients that had BC in Nigeria unveiled the following: 67.9% of women reported feeling inadequate as women six months after the procedure, and 79.0% reported a reduction in the frequency of intimate relationships. Compared to the national average divorce rate of 2.6%, 61.7% of the participants remained married three years after primary breast cancer treatment, while 38.3% reported having divorced or separated from their husbands (Michael et al., 2022). Sexual dysfunction cuts across all these dimensions, physiological, psychological and social causing a lot of anxiety that can lead to depression and marriage discordance, socially it can cause loss of identity, marital strain ending up with dysfunctional families(Mülkoğlu et al., 2022).

The above literature discussions have affirmed the high level of negative body image and perception the breast cancer survivors go through, after this current investigation it is hoped that some effective physical and psychosocial management structures may be put in place to support these individuals to improve their quality of life.

## **2.5 Rehabilitation support systems available to individuals with breast cancer post-mastectomy**

The implication of BC on quality of life (QOL) has been the subject of extensive research in the oncology domain (Bray et al., 2022; Sutter et al., 2021). Anxiety and depression are prevalent among breast cancer patients, which negatively impacts their quality of life (Archangelo et al., 2019). The implementation of psychological intervention may aid patients in adjusting to the breast cancer diagnosis and treatment process. Cognitive-behavioral techniques have demonstrated efficacy in ameliorating symptom management, emotional state, and disease coping mechanisms. (Grassi et al., 2019) This treatment is effective in reducing levels of anxiety and depression and enhancing overall QOL.

### **2.5.1 Counselling and stress reduction programs available post mastectomy**

In this section of the study we aim to establish effectiveness of counselling and stress reduction programs available to support these individuals who according to the literature searched have numerous physical, psychosocial and sexual health challenges that may be reduced or treated by screening and assessment of emotional problems and concerns of both the patient and the family and this ought to be part of every clinical intervention by health care professionals(Grassi et al., 2019)

Individuals diagnosed with breast cancer had little or no access to rehabilitation programmes and counselling at the time of diagnosis, according to a study conducted at a leading referral medical facility in Kenya (Gichuru et al., 2020). As a result, the study highlighted the importance of social support from friends, churches, employers, and support groups. Efforts to alleviate distress among cancer patients who have a negative body image encompass stress reduction programmes and supportive-expressive group psychotherapy (Grassi et al., 2019). The presence of a partner is of equal significance in fostering mutual understanding, particularly in the context of counselling sessions that aim at addressing problems with sexuality that may have profound psychological roots (Furrow et al., 2019).

Music therapy and relaxation training are two stress-reducing interventions that have been shown to improve anxiety and depression through physical and mental



relaxation, respectively (Zhou et al., 2019). Music therapy involves the clinical and evidence-based use of music interventions to achieve mental relaxation; by inhabiting attention channels in the brain with valuable, distracting, and soothing auditory stimuli, music can alleviate negative psychological states (Zhou et al., 2019). It entails methodically and increasingly attaining physical relaxation by enhancing muscle relaxation throughout the entire body; as a result, depression and anxiety levels in breast cancer patients who have undergone radical mastectomy are diminished (Zhou et al., 2019).

According to (Gichuru et al., 2020) at a major referral hospital in Kenya there are no proper counselling structures available to support these individuals with breast cancer post mastectomy to adapt. Professional health workers have been advised to help in the reduction of various psychological negative effects caused by body image experiences and perceptions through effective psychoeducation on coping skills and positive adaptations. This has already been implemented at the follow up clinics which has in place well-designed structures for psychosocial support.

### **2.5.2 Group therapy for breast cancer survivors**

The importance of group therapy is that the individuals are put together to learn from others who have similar struggles, they have a voice to speak and through group therapy they are able to develop social coping skills and grow in knowledge to enhance independence while coping with a life-threatening situation.

As stated in the study by Sung et al. (2021), the objective of social support groups is to enhance awareness regarding breast cancer by providing assistance to those afflicted with the disease, dispelling myths surrounding cancer, and emphasising that it is not fatal. Statistically, the incidence of breast cancer continues to rise around the world, which necessitates the formation of more healthcare professional support groups as well as volunteer organisations to assist those afflicted (Sung et al., 2021)

Bellver-Pérez et al. (2019) opined that breast cancer survivors (BCS) who had completed adjuvant medical treatment were compared to two psychological intervention study groups in a group therapy. Three months after the start of the therapy, their emotional state and quality of life (QOL) were assessed. Upon

evaluation of the results after three months, it was confirmed that both intervention groups contributed significantly to the improvement of the mood and quality of life of women with breast cancer. The observed reduction in anxiety and depression levels during the follow-up period was substantial, with anxiety levels improving marginally more than depression levels (Archangelo et al., 2019)

By confirming the findings of other studies involving group therapy with patients diagnosed with localised breast cancer, it was observed that those who received adequate support progressed through this phase more rapidly than those who did not. This finding further substantiates the notion that breast cancer survivors require both familial and social support, as supported by prior research (Bellver-Pérez et al., 2019).

The provision of care and support exhibits significant variation; therefore, educational initiatives that incorporate quality assessment may prove beneficial (Grassi et al., 2019). Extra social support is recommended (Padmalatha et al., 2021c). A study on the breast cancer experiences of Southern Thai women reveals that in addition to medical support from healthcare providers (as they were more likely to develop depression), these women also require family and social support to regain their sense of normalcy as social beings. Furthermore, the study found that in married participants, the most influential factor that helped the patients through this phase was social support (Padmalatha et al., 2021c).

Kenyatta National Hospital –CTC has support groups for BCS, these are structured support groups for patients with breast cancer and body image complications, a tool for effective psychosocial management of BCS. However, during this enquiry as we interview the patients, we shall be able to confirm the effectiveness of these groups.

### **2.5.3 Breast reconstructive surgery**

Breast reconstructive surgery (BRS) is an optional therapeutic procedure that may be performed as a delayed surgery or immediately following mastectomy. It may involve the use of autologous tissue, implants, or a combination of the two (Cheng et al., 2018). BRS is an ontologically safe procedure that enhances the patient's self-esteem without delaying the diagnosis of local recurrence or increasing the risk of relapse. Breast reconstruction subsequent to mastectomy has the potential to enhance a

woman's quality of life and body image, thereby contributing to a less distressing rehabilitation journey than mastectomy alone. This is particularly true for younger women, who place a higher value on body image in comparison to their older counterparts (Archangelo et al., 2019).

Annually, more than 100,000 women in the United States go through radical mastectomy, with more than half opting for immediate reconstruction of their breasts (Rosenkranz et al., 2021). Information regarding breast reconstruction after mastectomy in countries in Africa is limited (Gichuru., et al 2020) In Kenya, one of the referral hospitals Kenyatta National Hospital (KNH), recorded minimal numbers of an average of two breast reconstructive surgery done per year for the past five years (KNH Medical Records Statistics Registry 2022 March)

Females who undergo mastectomy without breast reconstructive surgery may develop a sense of inferiority complex due to the symbolic nature of the breast, which represents the woman's self-perception (Archangelo et al., 2019). Breast reconstructive surgery (BRS) has been observed to yield favourable outcomes across various dimensions of quality of life (QOL), with particular emphasis on body image, which is typically highly valued by young women. Archangelo et al. (2019) suggest that BRS may enhance self-esteem without delaying the diagnosis of local recurrence or increasing the risk of relapse. Patients who underwent BRS subsequent to mastectomy reported improved body image, enhanced sexual function, and a reduction in depressive symptoms in comparison to those who had undergone mastectomy exclusively. Additionally, the findings indicated that sexual dysfunction was more prevalent in the mastectomy group and was correlated with a higher level of education and the absence of a married partner (Archangelo et al., 2019). In addition to reshaping the breast, breast reconstruction surgery (BRS) restores a woman's sense of self, beauty, and sexual desires, thereby influencing her quality of life. As a result, for optimal patient management, a BRS recommendation should be provided to breast cancer patients who have undergone a mastectomy (Gichuru et al., 2020).

There is currently an absence of published data in Kenya regarding the relationship between breast reconstruction following mastectomy and improved sexual function,

body image, or reduced depressive symptoms compared to patients who underwent mastectomy alone (Gichuru et al., 2020).

Archangelo et al. (2019) found that the majority of women who participated in this qualitative investigation reported that reconstruction of their breasts not only eliminated the need for prostheses and restricted clothing options, but also, above all else, provided a way to regain a sense of completeness and normalcy, which enhanced body image and self-esteem.

The research demonstrates that breast reconstruction subsequent to mastectomy results in enhanced quality of life among individuals diagnosed with breast cancer. The results of this study have influenced the Brazilian public health system to incorporate breast reconstruction procedures into the standard treatment regimen for breast cancer patients (Archangelo et al., 2019). With any luck, the Kenyan health system will incorporate BRS as a standard procedure following mastectomy in order to enhance the quality of life for breast cancer survivors in the wake of this investigation.

Despite constituting an important part of care for those with BC, the level of reconstruction of breast following surgical incision remains low at the national public referral medical institution in Kenya, according to the findings of this hospital-based study (Gichuru et al., 2020). Efforts should be heightened to increase awareness of this specialised reconstructive surgery among this patient's category, surgical stakeholders, and the general society.

## **2.6 Theoretical framework - Roy's Adaptation Model (RAM)**

The study's theoretical framework is based on the Roy Adaptation Model, which was originally formulated by Sister Callista Roy in 1970 and has since undergone further refinement. Individuals are portrayed by the Roy Adaptation Model as holistic adaptive systems that are in constant interaction with their internal and external environments. The primary objective of the human system, in accordance to this model, is to preserve integrity despite environmental stimuli. Therefore, the objective of nursing is to promote effective adaptation (Roy, 2021).

The founding principles of the Roy Adaptation Model are as follows: 1) Adaptation is a fundamental objective of nursing that encompasses the strategies employed by both individuals and groups to constructively react to alterations in their surroundings or to establish a symbiotic relationship between the human and the environment. 2) Individual—Considered a bio-psycho-social being in perpetual interaction with a dynamic surroundings, employing both innate and acquired mechanisms to adjust to the environment; 3) The environment serves as the stimulus and encompasses all conditions, circumstances, and influences that surround and impact the growth and conduct of individuals and collectives, whether they are direct, indirect, or contextual in nature. 4) Health is indicative of the results of adaptation and is delineated along a continuum from well-being to illness. A condition of being and the process of being and becoming a unified and entirety being that reflects the interdependence of the individual and the environment is health. 5) Nursing, whose principal responsibility is to facilitate the health and successful adaptation of individuals and/or groups (Roy, 2021).

The foundational tenets of the Roy Adaptation Model are as follows: an individual is a bio-psycho-social being, which means they are perpetually exposed to a changing environment; in order to adapt favourably to environmental changes, they utilise a combination of innate and acquired mechanisms that are psychological, biological, and social in nature; and to do so, they must adapt. The Roy Adaptation Model identifies four modes of adaptation: physiological needs, self-concept, and role functions.

In nursing, the Roy Adaptation Model is frequently implemented. The nurse implements the model by adhering to Roy's six-step nursing process: (1) Evaluate the actions demonstrated in accordance with the four adaptive modes: interdependence mode, self-concept–group identity mode, physiological-physical mode, and role function mode. (2). Determine and classify the stimuli that elicit these behaviours. (3). Diagnosis in nursing should be predicated on the individual's adaptive state. (4). Set objectives to encourage adaptation. (5). Execute interventions designed to regulate stimuli in order to facilitate adaptation and (6). Assess the accomplishment of adaptive objectives (Ursavaş et al., 2021). By manipulating the stimuli rather than the

patient, the nurse facilitates the individual's interaction with their surroundings, thus promoting health, according to Roy (2021).

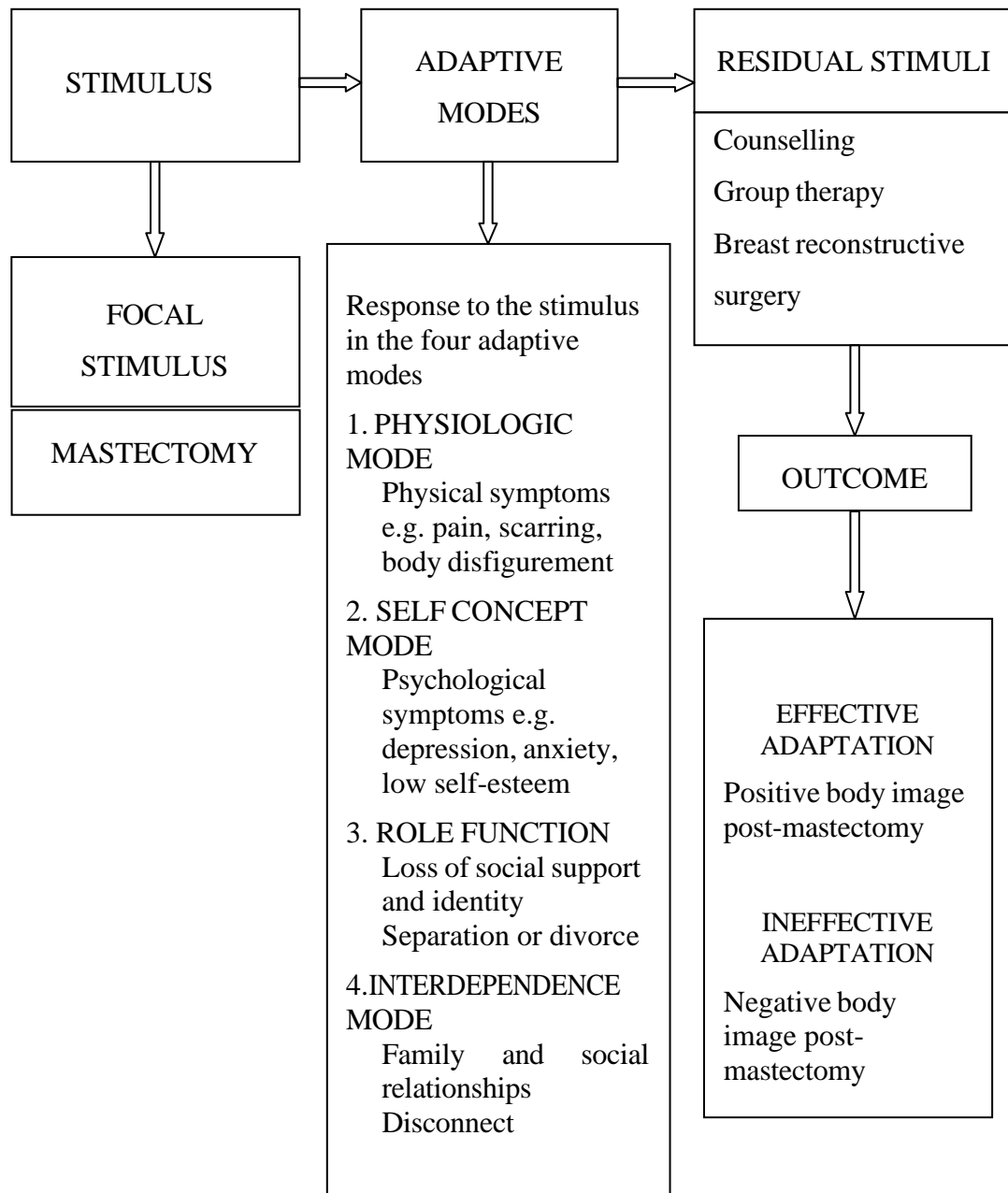
The focal stimulus, which in this study is a mastectomy, is one of three classes of stimuli that the human system is exposed to according to Roy's adaptation model. The contextual stimulus, which is known to affect the individual, refers to all other stimuli from the internal and external environments of the human system that can be identified as having a positive or negative impact on the body. The Roy adaptation framework in accordance with Sister Callista Roy (2021) demonstrates the interconnectedness of numerous variables and concepts.

The four adaptive modes are significant in this study as the experiences and perceptions of the individuals post mastectomy may be affected in all the three modes. In the physiological mode are the physiological body symptoms affected by negative body image occurring as a result of mastectomy like pain, lymph edema, scarring and disfigurement; self-concept mode is about the feelings and beliefs about mastectomy due to negative body image effect like low self-esteem, depression and anxiety and role function mode are the social roles affected by mastectomy like loss of social support, loss of identity, separation or divorce and interdependent relationships affected by lack of love in the family units or others causing family disharmony and disconnect in relationships with others. The third stimulus is the residual stimuli which include the external factors which in this study are counselling, group therapy and breast reconstructive surgery which may moderate the adaptation process. According to Roy's theory the adaptation finally emerges into either positive or negative individual behavior after manipulation of internal and external environment by the stimuli which are relevant to this study.

The health care professionals should plan to discuss these concerns with the patients advising them on temporary remedies like well-designed prosthesis and breast reconstructive surgery that could be a possible solution to most of this physical and psychological distress due to negative body image (Gichuru et al., 2020), this study recommended that adequate counselling before, during and after surgery is important in order to help the patients adapt to their new medical condition.

The relevance of Roy's adaptation theory was the application of the concepts of this theory in this qualitative study encompassing on effective and ineffective adaptations and behavioral responses on human adaptive system in the physiological, physical, self-concept, group identity, role function in the normal family and community set ups, and interdependence or interpersonal relationships with others; and how they could be manipulated to promote positive life adjustments and significantly influence negative behaviors that adversely affect their perceived life satisfaction.

The research instrument which was the interview guide questions was derived from the concepts of Roy's adaptation model theory, which guided the data analysis procedure and helped in the construction of themes and subthemes.



**Figure 2.1: Roy Adaptation Theoretical Framework**



### **3.0: CHAPTER THREE: RESEARCH METHODOLOGY**

#### **3.1 Research paradigm**

The constructivism paradigm was utilised in this investigation, which involved the collection of qualitative data, thematic analysis, interpretation, and conclusion drawing. The philosophical paradigm of constructivism is closely linked to the qualitative research approach. This is the case because, utilising various data collection agents, the paradigm attempts to grasp the phenomenon being investigated from the viewpoint or as experienced by those taking part. Furthermore, the investigator extracts meanings of the aspect being investigated by relying upon both his personal experiences and those of the study participants. By evaluating what is said, the researcher determines the actual facts. In an effort to ascertain the actual condition of the subject matter being investigated, he occasionally participates in the activities conducted by local inhabitants in their natural environments, either so that he may personally encounter it or observe others doing so. Furthermore, constructivists, similar to qualitative researchers, argue that reality is subjective due to the fact that it is constructed from the unique perspectives of study participants, who are therefore numerous or diverse. Moreover, the researcher derives significance from events by means of social and cultural interactions with others. The majority of the time, research guided by the constructivist philosophical paradigm commences with open-ended inquiries formulated as research questions. Subsequently, tentative or sound conclusions are derived from the results of the study.

#### **3.2 Study design**

A cross-sectional qualitative survey was utilized. Data collection was through face-to-face in-depth interviews.

#### **3.3 Study area**

Originally known as the Native Civil Hospital, Kenyatta National Hospital (KNH) was established in 1901 with a total of fourty cribs. It was renamed the King George VI Hospital in 1952, in honour of the United Kingdom's King George VI. The settlers were presently attended to by the European Hospital, which is presently known as

Nairobi Hospital. Following independence, the establishment was inaugurated as Kenyatta National Hospital, in honour of the nation's first president, Jomo Kenyatta. The primary referral and teaching hospital, it provides services not only to the nation but also to the broader East African community. Kenyatta National Hospital has a bed capacity of over 2000 and employs more than 6,000 individuals. Situated in Upper Hill, approximately 3.5 kilometres west of Nairobi's central business district, the hospital functions as a training facility for numerous institutions, such as the Kenya Medical Training College, the University of Nairobi, and numerous others from across the nation.

One of the hospital's key departments is the Cancer Treatment Centre (CTC), which provides advanced comprehensive cancer treatment and other cancer-related services. The cancer treatment centre provides a range of services to patients diagnosed with cancer, encompassing both inpatient and outpatient settings. These services comprise assessment of new patients and referrals, admissions for chemotherapy, review of patient results, radiotherapy marking, outpatient chemotherapy, review of nuclear patients, patient follow-up, joint radiotherapy and ear, nose, and throat clinic, and emergency radiotherapy (KNH, 2022). Additionally, it has an inpatient unit where patients receive long-lasting chemotherapy. It has the patient numbers from diverse backgrounds drawn from across the nation receiving specialized management for various types of cancers including breast cancer, it also has specialized personnel and the best facilities in the country.

The rationale for choosing Kenyatta National Hospital was that it serves as a national referral hospital at the site due to the ability to access the study participants, since the researcher attended the clinical placement experience in the hospital, in addition, the researcher anticipated that the participant interviews for the study would take place in one location due to limited duration to carry out the study, this made the site more convenient to the researcher.

### **3.4 Study population**

Those targeted for involvement consisted of patients who had undergone mastectomy and were receiving chemotherapy, hormonal therapy or radiotherapy at the Cancer

Treatment Center at Kenyatta National Hospital between June 2021 and October 2022.

### **3.5 Inclusion criteria**

- i. Patients that had BC who were attending follow-up care at Kenyatta National Hospital after undergoing mastectomy.
- ii. Patients undergoing management for breast cancer after mastectomy.
- iii. Patients who were adults (18 years and above).
- iv. Patients who gave consent to be interviewed.

### **3.6 Exclusion criteria**

- i. Patients who were critically ill and those not able to respond to interviews.
- ii. Individuals afflicted with any type of cognitive impairment due to dementia or the use of sedatives.

### **3.7 Sample size determination**

The study sample size was determined by the principle of data saturation. The data collection continued till a point where no new data and no additional insights were being generated, at which point data saturation was considered as having been achieved (Braun and Clarke 2019; Wagoro & Duma, 2021).

### **3.8 Sampling procedure**

Purposive sampling was employed to select participants from both inpatient and outpatient departments. The researcher conducted an examination of the nursing notes and patient files in order to identify any participant-reported challenges subsequent to mastectomy. Patients who met the study's eligibility criteria were selected using the researcher's discretion. Subjects were chosen by the researcher based on the value of their responses to the research. Individuals who were 18 years of age or older, diagnosed with breast cancer, satisfied the inclusion criteria, and expressed willingness to participate were systematically selected in a sequential manner. Consent was obtained during clinic days at the cancer clinic follow-up unit (LINAC), the out-patient chemotherapy administration unit (GFC), and the in-patient

chemotherapy and radiotherapy unit (GFD). Purposive sampling technique, according to Sutton and Austin (2015), allows the researcher to apply his/her own judgement on selection of participants eligible for the study on the basis of required characteristics and hence is able to select those who were in a position to provide useful information for the study.

### **3.9 Participants' recruitment procedure**

Once the approval from KNH-UoN ERC and NACOSTI were granted, management of Kenyatta National Hospital was approached for permission to collect data by the researcher. Staff and potential study participants were also informed of the study through the use of posters and verbal communications. Subsequently, prospective participants were provided with pertinent study information in an effort to pique their interest and solicit their consent to partake in the research. The researcher enrolled a sufficient sample of participants in accordance with the study's objectives and design, obtained informed consent while upholding ethical standards, retained participants until study completion, and identified eligible participants after providing a thorough explanation of the study to potential participants. Consecutively recruited from both the outpatient and inpatient areas, study participants who satisfied the inclusion criteria and were permitted to partake were segregated from the other patients and assigned to a separate room.

### **3.10 Consenting Procedure**

Written initial approval was obtained from the KNH-UoN research ethical committee and NACOSTI. In order to safeguard confidentiality and minimise service disruptions, the researcher ensured that all participating breast cancer survivors provided written consent subsequent to an explanation of the research's nature. To facilitate the assignment of a designated room within the unit for the consenting procedures and interviews, the researcher coordinated with the unit supervisor. The researcher reviewed the consent form and participant information statement sheet with each individual. The participants were granted the opportunity to inquire about any aspect of the study that required clarification. The participants were guided through the consent declaration statement. Upon the participant's declaration of

comprehension regarding the agreed-upon terms and her expression of interest in participating in the study, she was presented with a consent form for signature.

### **3.12 Data collection**

#### **3.12.1 Research instrument**

The researcher collected data through the use of a semi-structured interview guide (refer to Appendix 5), which served as a framework for data collection throughout the discussions. The interview procedure was delineated in the guide, which comprised structured probing questions aligned with the study's concepts, follow-up inquiries, and concluding exit questions for the participants. The queries were brief, uncomplicated and straight forward to preclude researcher's or respondent's biases and ensure honesty as described in section 3.15 on study limitations.

#### **3.12.2 Pre-test of the study tool**

Evaluation of the survey tool was undertaken within KNH at the gynaecological surgical unit fifth floor separate from CTC to avoid familiarity and biased responses. The collected data underwent analysis in order to identify any required corrections. Sophisticated guidance was sought in order to enhance the research instrument.

#### **3.12.3 Data collection procedure**

Patients with cancer and who were adults provided the study data and attending KNH CTC after consenting to the procedure which was explained in details to allow the participants to make decision before giving informed consent. The study recruited consenting participants who participated individually in the in-depth interview for 30 to 45 minutes in a private room at the Cancer Treatment Centre. Prior to recording, consent was obtained from the participant and permission was sought to conduct an audio recording of the interview.

The researcher adhered to an interview guide while conducting an in-depth interview with the participant of the study. The interview protocol was delineated in the guide, comprising structured inquiry queries, follow-up inquiries, and concluding exit questions. The inquiries were uncomplicated, concise, and unambiguous in order to

prevent any partiality and guarantee excellence. The consent to utilise an interview room located inside the Cancer Treatment Centre came from the nurse manager of the oncology unit. The participants provided informed consent prior to the interview, after which they were escorted into the interview room situated inside the unit where the discussion was conducted. To maintain strict confidentiality, the room was occupied solely by the investigator and the study participant. The interviews were guided and pertinent information was captured using an interview guide. Each session was audio-recorded using a Sony ICD PX333 digital voice recorder, and the transcription was promptly completed to prevent the omission of crucial dialogue details. Brief annotations were made throughout the dialogues and in their aftermaths for the purposes of reflection and to guarantee the standard of the work. The utilisation of audio-recorded interviews allowed the investigator to focus on the subjects of the study (Mowers, 2003). A digital voice recorder was utilised to capture the audio of each session, and notes from interviews were diligently taken to ensure the highest standards of quality.

### **3.14 Data management plan**

#### **3.14.1 Data cleaning and entry**

Data cleansing entails iterative cycles of screening, diagnosis, treatment, and documentation in order to detect error patterns in the gathered data entries and correcting them to reduce future errors (Sutton et al., 2015). The researcher performed a three-stage process on the recorded data, entailing recurring screening cycles, correcting, and doing edits on identified abnormalities in the data. The audio-recorded data was transcribed and entered into the computer program (QSR NVivo version 12) for thematic analysis each day of data collection. Social demographic and clinical characteristics data was checked for completeness analyzed and summarized descriptively. All records containing the patient's demographic information, comments and transcripts were gathered and annotated as necessary.

#### **3.14.2 Data storage**

To maintain the confidentiality of the participants, measures were taken to safeguard their anonymity. This was achieved by assigning consecutive serial codes to all

interview notes, transcript printouts, and audio recordings, which were subsequently stored in a securely locked drawer. Furthermore, all data inputted into the computer system was securely stored using password protection measures, ensuring that only the principal investigator had authorised access to it. Upon completion of data entry and cleaning, the researcher's notes and the verbatim printouts of the respondents were securely stored in a filing cabinet. In order to maintain security and uphold the principle of confidentiality, exclusive access to the keys of the filing cabinet was restricted to the lead researcher.

### **3.14.3 Data analysis, presentation and measurement**

A descriptive analysis was conducted by summarizing sociodemographic and clinical characteristics through the use of frequency distribution and percentages, based on the demographic data entered into the computer. Concurrently with and following the interviews, as suggested (Parahoo et al., 2014), data collection and analysis were conducted. The phenomenon description followed Colaizzi's (1978) method, which, according to (Morrow et al., 2015; Wirihana et al., 2018), can be relied upon to examine the experiences of individuals, aid in the development of therapeutic policies, and facilitate patient-centered management.

During the interview, the researcher employed verbatim text quotes from participants (informant feedback/respondent validation) to provide further elucidation and bolster conclusions, thereby establishing the study's credibility, veracity, and precision. The researcher transcribed into text format the audio recordings obtained through in-depth interviews. Subsequently, the transcripts were reviewed in conjunction with the audio recordings to identify transcription errors and omissions of crucial details. These were rectified. The analysis process was guided by the subsequent steps;

- i. Step one: The investigator spent a few days rereading the interview transcripts and transcripts in order to gain an understanding of the phenomenon. This ensured that the statements provided by the participants remained the central focus of the analysis. To prevent any confusion during the analysis, transcribed data and interview notes were promptly organised and filed in accordance with the study goals. The researcher employed thematic analysis

(Clarke et al., 2016) to examine the data in accordance with the study objectives and emerging themes.

- ii. Step two: entailed in the process of extracting significant statements pertaining to the phenomenon. A significant statement was defined as one that was directly related to the participant's experience of the phenomenon. The context of each statement was maintained during the extraction of such statements from transcripts (Tapper, 2011). The contextualization of each statement involved appending the participant number, the paragraph number, and the page number of the transcript, which ensured the preservation of anonymity.
- iii. Step three: Following the categorization of data, the researcher assigned codes to delineate the substance. By constantly comparing significant statements in order to identify patterns that could be used to derive meanings, the process ascribed significance to the significant statements. Over time, the researcher refined and interpreted the patterns while consulting the initial notes to acquaint herself with the transcript's content and identify potential themes.
- iv. Step four: In order to identify the existence of particular words, concepts, or themes within significant statements that shared comparable phrases and their derived meanings, the researcher conducted an analysis of the qualitative data. These findings were then consolidated into theme clusters. The themes were subsequently derived by combining clusters of related themes. Colaizzi (1978) underscored the criticality of cross-referencing the identified themes with the original transcripts. This was accomplished by reviewing the transcripts to check the authenticity of the themes in the study.
- v. Step five: Through the integration of all the findings, an in-depth explanation of the phenomenon at hand was generated (Polit and Beck, 2014). Numerous reexaminations of the transcripts, thematic clusters, and themes were conducted in order to scrutinize any inconsistencies or alternative viewpoints and guarantee an accurate understanding of the full description. The investigator and those who participated verified the thorough account of the investigated occurrence that resulted from the fusion of the themes.
- vi. Step six: The objective of this stage was to eliminate any superfluous or inappropriate depictions of the phenomenon's fundamental structure (Shosha,



2012; Wirihana et al., 2018). Upon conducting an exhaustive examination and eliminating superfluous data, the underlying framework of the phenomenon was discerned.

- vii. Step seven: In order to validate the work by incorporating participant feedback, the fundamental structure and comprehensive description of the phenomenon were revised to ensure that they more accurately reflected the experiences of the participants. In conclusion, verbatim quotes were used to illustrate and reflect the participants' perspectives and life experiences regarding the phenomenon under investigation. The researcher retained both the data obtained from the in-depth interviews and the oral statements provided by the participants throughout the interview process.

### **3.15 Study limitations**

**Interviewer bias:** The manner in which the interviewer poses inquiries has the potential to influence the responses provided by the participants. This was mitigated through the implementation of straightforward interview questions in the guide. The investigator avoided employing leading questions and expressing personal opinions regarding the experiences of the participants.

**Language Barrier:** Differentials in language may impede communication. This was circumvented through the use of an interpreter or the official languages (Swahili or English) during the interview.

**Responder bias:** Respondents may provide misleading or deceptive responses to questions. They might feel compelled to provide responses that are socially acceptable, or their responses might be influenced by their health status or the hospital environment. The investigator endeavoured to inquire about the participant's comprehension while emphasising the significance of candidness throughout the interview. Depending on the patient, the investigator utilised prompting queries in the guide for the interview and asked open-ended questions to make certain that the participant's responses were straightforward.

### 3.16 Dissemination plan

The investigator is required to submit copies of the final research project document to the library of the University of Nairobi School of Nursing Sciences. Subsequently, the University of Nairobi repository will publish the findings. The researcher shall additionally strive to disseminate the results through publication in nursing journals and attendance at reputable academic and scientific conferences.

### 3.17 Ethical considerations

- i. **Autonomy:** Initial authorization in writing from both the KNH-UoN research ethics committee and NACOSTI was obtained. The researcher took measures to ensure that all participants were sufficiently informed regarding their rights and the anticipated advantages of the research. Prior to their involvement, the researcher obtained informed consent from all of the respondents. No inducement or coercion was used to motivate the participants to participate.
- ii. **Anonymity and Confidentiality:** The researcher implemented measures to safeguard the confidentiality and anonymity of the participants. These precautions went beyond mere protection of their names, encompassing the prohibition of self-identifying statements and information as well. Confidentiality and anonymity were crucial in safeguarding the participants against potential harm. In order to maintain the privacy and dignity of the participants, their identities and names were withheld throughout the data collection, analysis, and reporting of the study's results. Ensuring the preservation of privacy and confidentiality throughout the interview session, data analysis, and dissemination of the findings was a top priority.
- iii. **Non-maleficence:** Throughout the data collection process, the researcher took measures to mitigate any potential harm that might occur by abstaining from causing physical or psychological harm to the respondents. In order to maintain this stance, the researcher refrained from posing humiliating inquiries, enduring disappointment, or coercing participants into divulging information that might induce fear or anxiety in the respondents. The investigator debriefed the respondent or respondents at the conclusion of the

interview by elucidating the precise purpose of the study and the reasons why the disclosure might elicit intense emotions and anxiousness.

- iv. **Beneficence:** Beneficence is a moral principle that pertains to engaging in actions that advance the well-being and security of others while also helping them (Pieper et al., 2016) the researcher protected participants from harm by respecting and strictly abiding by the ethical conduct of not harming but maximizing any possible benefits.
- v. **Justice:** Justice as a moral principle entails the concepts of equity and impartiality. A fundamental and distinguishing characteristic of this principle is its commitment to safeguarding participants from exploitation and abuse. The researcher demonstrated a commitment to justice by acknowledging the participants' vulnerabilities and valuing their input to the research. The researcher upheld the principle of justice by protecting the most vulnerable participants, including prisoners, the elderly, and those with mental illness, and by listening to the perspectives of disadvantaged and minority groups.

### **3.18 Trustworthiness of the research**

*Rigor:* entails the researcher's endeavour to demonstrate excellence and their commitment to precision and attention to detail. Parahoo (2006) posits that scholars desire their findings to accurately represent the phenomenon under investigation and to make a valuable contribution to the body of knowledge. As this investigation was qualitative in nature, a model were adopted by the researcher (Lincoln et al., 1985) to enhance its credibility. Transferability, dependability, credibility, and confirmability were all included. Within the realm of quantitative research, these terms denote validity and dependability.

*Credibility:* Is contentment in the veracity of the facts and the interpretations thereof. As stated by Polit and Beck (2010), member checking is an essential method to establish legitimacy in qualitative studies. This is considered a fundamental objective of qualitative research. This was achieved through ongoing scrutiny, inquiry, and theoretical interpretation of the results to ascertain that the research objectives of the study had been satisfactorily achieved.

*Dependability:* This describes the data's capacity to maintain stability over time. The researcher implemented an audit trail in order to bolster the study's dependability. The process of data analysis was validated by two outside observers who possessed expertise in qualitative research. The researcher further expounded upon the data gathering and analysing procedures, which the reader may peruse in order to assess the rigour of the research.

*Confirmability:* In order to accurately reflect the information provided by participants, data must provide clarity for all information. In order to validate confirmability, the researcher employed verbatim text extracts from interviews with participants that bolstered conclusions. The integrity of the audit was upheld through the documentation of all actions and decisions undertaken, enabling subsequent investigations by other researchers to be traced back to them.

*Transferability:* The utility of qualitative study findings in relation to analogous groups or circumstances (Parahoo, 2006). To ensure transferability, the demographic characteristics of those who participated and the study context were explained thoroughly. Entry of participants with different demographic characteristics and reports of the study processes were done carefully.

*Generalizability:* As a result of the limited sample size, generalizability concerns arise. Nevertheless, Parahoo asserted that the study's potential utility extends well beyond the examined sample if it is executed with precision. While qualitative research findings may lack generalizability, they can still hold significance or relevance for individuals facing comparable circumstances (McKenna and Copnell, 2019). In pursuit of ensuring transferability, the researcher conducted investigations in accordance with the suggested protocol. It was anticipated that data saturation would guarantee the completion of the data and capture crucial elements of the phenomenon for the purpose of interpretation in this study.

### **3.19 Covid-19 prevention/safety measures**

In light of the Covid-19 pandemic, the investigator took every precaution to safeguard the participants by adhering to the guidelines and preventive measures prescribed by the Ministry of Health during the duration of data collection. The protocols

encompassed screening the participants for signs and symptoms of Covid-19, including but not limited to fever, nasal congestion, cough, and sore throat, prior to admitting them into the data collection area. It was ensured that the interviews used for data collection were carried out in a room that was adequately ventilated and spacious, with the investigator maintaining the recommended physical and social distance of 1.5 metres between each participant and the subject.

Prior to and following the in-depth interview sessions, all participants, including the investigator, were required to don face masks and wash their hands with soap and running water or alcohol-based sanitizer containing a minimum of 70% alcohol concentration. Constant use of appropriate personal protective equipment was maintained throughout the duration of data collection. Daily Covid-19 testing was performed to rule out infection during the researcher's data collection at the hospital. Nevertheless, the researcher did not exhibit any indications of Covid-19 throughout the entirety of the data collection phase.

## **4.0: CHAPTER FOUR: RESEARCH FINDINGS**

### **4.1 Introduction**

This chapter presents findings on the demographic characteristics of the study participants. It also describes identified themes and subthemes that emanated from interviews with the study participants relating to their experiences after undergoing mastectomy.

An aggregate of 10 patients who had undergone mastectomy attending KNH's Cancer Treatment Center for follow-up care clinics between June 2021 and October 2022 took part. The study participants were selected using purposive sampling technique and the study sample size was determined on the basis of the principle of data saturation. Data saturation in the study was reached when data obtained from further interviews with the participants did not yield new insights or meanings. The credibility of this study was enhanced by high rate of response from the participants.

The chapter begins by highlighting the characteristics of the study participants, both socio-demographic and clinical characteristics under Section 4.2. The remaining parts of the chapter are organized as per the study objectives. Hence, section 4.3 highlights results on the physiological experiences and perspectives of the women post-mastectomy; section 4.4 highlights results on the psychological experiences and perspectives of the women post-mastectomy; section 4.5 highlights results on the sociological experiences and perspectives of the women post-mastectomy while section 4.6 highlights results on the rehabilitation support systems available to the women post-mastectomy.

### **4.2 Study participants' characteristics**

#### **4.2.1 Socio-demographic characteristics of the participants**

The participant's socio-demographic attributes were evaluated.

Results indicated that majority (80%, n = 8) of the participants were aged 40-64 years, most lived outside Nairobi (70%, n = 7) and that majority had basic education level (primary – 40%, n = 4; secondary – 40%, n = 4).

Further, most of the participants were self employed (60%, n = 6), half (50%, n = 5) were married, 30% (n = 3) were widowed while 20% (n = 2) were single and most had 1 - 3 children (50%, n = 5) or 4 - 6 children (40%, n = 4).

The results also indicated that all (100%, n = 10) of the participants were Christians and almost all of the participants paid for their treatment using NHIF alongside out-of-pocket payments/cash (90%, n = 9). Results are presented in Table 4.1.

**Table 4.1: Socio-demographic characteristics of the participants (n=10)**

Demographic attributes		Frequency (N)	Percentages
Age	18 - 39 years	1	10.0
	40 - 64 years	8	80.0
	65 years and above	1	10.0
	<b>Total</b>	<b>10</b>	<b>100.0</b>
Place of residence	Within Nairobi	3	30.0
	Outside Nairobi	7	70.0
	<b>Total</b>	<b>10</b>	<b>100.0</b>
Highest education level	Primary	4	40.0
	Secondary	4	40.0
	Tertiary	2	20.0
	<b>Total</b>	<b>10</b>	<b>100.0</b>
Employment status	Formally employed	1	10.0
	Self-employed	6	60.0
	Unemployed	3	30.0
	<b>Total</b>	<b>10</b>	<b>100.0</b>
Marital status	Married	5	50.0
	Single	2	20.0
	Widowed	3	30.0
	<b>Total</b>	<b>10</b>	<b>100.0</b>
Number of children	1 – 3	5	50.0
	4 – 6	4	40.0
	More than 6	1	10.0
	<b>Total</b>	<b>10</b>	<b>100.0</b>
Religious faith	Christian	10	100.0
	<b>Total</b>	<b>10</b>	<b>100.0</b>
How they paid for treatment	NHIF & out-of-pocket payments	9	90.0
	Private health insurance	1	10.0
	<b>Total</b>	<b>10</b>	<b>100.0</b>

#### 4.2.2 Clinical characteristics of the participants

This section illustrates the clinical characteristics of the participants as self-reported by them. The results indicate that majority (80%, n = 8) of the participants had visited KNH's Cancer Treatment Center for treatment, most underwent the mastectomy either 12 - 24 months ago (40%, n = 4) or more than 24 months ago (40%, n = 4) and that most (60%, n = 6) of the participants were currently receiving chemotherapy or radiotherapy, as depicted in Table 4.2.

**Table 4.2: Clinical characteristics of the participants (n=10)**

Clinical care attributes		Frequency (N)	Percentages
Reason for the hospital visit	Consultation	1	10.0
	Treatment	8	80.0
	Follow-up clinic	2	20.0
	<b>Total</b>	<b>10</b>	<b>100.0</b>
When they had the mastectomy	0 - 12 months ago	2	20.0
	12 - 24 months ago	4	40.0
	> 24 months ago	4	40.0
	<b>Total</b>	<b>10</b>	<b>100.0</b>
Treatment(s) they were currently on	Surgery	2	20.0
	Chemotherapy or radiation therapy	6	60.0
	Hormonal therapy	2	20.0
	<b>Total</b>	<b>10</b>	<b>100.0</b>

#### 4.3 Physiological experiences and perspectives of the women post-mastectomy

The study explored the physiological experiences and perspectives of the study participants post-mastectomy. In this study, physiological experiences and perspectives were defined as the physical functioning status of the women after undergoing mastectomy and aimed to find out whether the women were able to continue performing normal physical activities/roles in their lives without much difficulty post-mastectomy. Therefore, a review of the women's physiological experiences and perspectives post-mastectomy explored the participants' views regarding how undergoing mastectomy had affected them physically including their physical body image and their capacity to engage in normal activities of daily living such as one's work. According to Iddrisu et al. (2020) and Lundberg et al. (2022),



physiological experiences and perspectives in the context of breast cancer patients signifies the women’s physical functioning capacity following treatment and therefore denotes any limitations imposed on these patients’ physical functioning ability by the form of treatment received.

The primary focus of discussions with the participants was on how mastectomy had affected them physically. Each transcript was scrutinized several times to identify key phrases which were then assigned appropriate codes. The phrases were then reduced and subsequently grouped on the basis of similarity in thoughts, ideas and meaning into clusters. The clusters were then organized into concepts which in turn were grouped into themes and sub-themes. The main theme and sub-themes in relation to the participants’ physiological experiences and perspectives post-mastectomy are summarized in Table 4.3.

**Table 4.3: Theme and sub-themes on participants’ physiological experiences and perspectives post-mastectomy**

<b>Research objective</b>	<b>Theme and sub-themes</b>	<b>Definition of the theme &amp; descriptors</b>
To explore physiological experiences and perspectives of individuals with breast cancer who have undergone mastectomy at Kenyatta National Hospital	Diminished physical strength/functioning  <i>Sub themes</i> Altered body image Disrupted work life Disrupted sexual life	<i>Diminished physical strength or functioning</i> denoted experiences of general body weakness, low energy levels and increased difficulties in performing normal activities of daily living among the participants following undergoing mastectomy. <i>Altered body image</i> denoted the adverse effects of mastectomy on the women’s physical appearance. <i>Disrupted work life</i> denoted the participants’ inability to continue with their normal work life following mastectomy <i>Disrupted sexual life</i> denoted loss of desire in sexual intimacy among the participants as a result of the mastectomy

During the discussions with the study participants, it emerged that reduced physical strength/functioning constituted the most common physiological experience among the study participants post-mastectomy. From the findings, majority of the study participants indicated that they were not able to perform at the same physical level as they were prior to the mastectomy. Most also indicated that they experienced low energy levels, general body weakness and that their bodies had lost its strength. In general, the participants concurred that they were no longer able to perform physically demanding tasks or work after undergoing the mastectomy.

Three sub-themes emerged that related to how the mastectomy had affected the participants physiologically. These were altered body image which represented changes in body appearance as a result of the mastectomy; disrupted work life which represented the participants' inability to resume normal work or their usual livelihoods post-mastectomy and disrupted sexual life which represented how the mastectomy had affected the participants' sexual relations with their partners. The three sub-themes are as described in the following subsections.

#### **4.3.1 Altered body image**

Altered body image formed the first sub-theme to emerge from the data as being one of the physiological experiences and perspectives of the study participants post-mastectomy. According to the findings, the participants indicated that their body appearance was adversely affected by the mastectomy procedure due to the gap left on the removed breast. Most of the participants expressed having concerns over their body appearance owing to the distortion brought about by the missing breast. Indeed, some participants expressed disappointment and displeasure with their physical appearance owing to the loss of their breast following the mastectomy. These negative sentiments over the altered body image among the study participants can be understood given that breasts are an important intimate part of female body and carry great significance to their maternal roles, outlook as well as perceived beauty. Their shared experiences and perspectives in relation to the changed body appearance are as illustrated in the following verbatim excerpts;

“... When I wear my clothes they fall on one side and distorts the shape, I went to a tailor to make for me something to fix to the gap left so that my dresses

can fit me well. So it affects me because when I wear, say, a dress, the dress falls on one side and the shape is distorted.” (P3)

“...My appearance changed because I just noted that part of my breast is missing ... one side has a breast and one does not have, it is an awkward feeling and uncomfortable one too.” (P4)

“... I feel very bad that I lost my breast, it has changed my body appearance, somewhat in a bad way, which bothers when I think about it.” (P6)

“... the problem was there after mastectomy. It was too hard for me to leave the hospital, how do I go back home without my breast and I came with my two breasts ...” (P7)

“... my body appearance has already changed. It is not look like I looked before. Now it is like I am bent on one side. Even when I walk, I walk like I am being pushed towards one side, which makes me just want to sit inside and I do not want to go out.” (P8)

“... It has really changed, as I said there is this imbalance... and then you are not comfortable, may be when a visitor comes to the house, the first thing you do is to run to the bedroom to wear a bra, so that she or he will not see the weakness in you, and when you are going somewhere you just feel, it hurts when you see people are jovial but internally there is something telling you that you are not normal.” (P10)

#### **4.3.2 Disrupted work life**

From the findings, disrupted work life emerged as another leading physiological experience among the study participants post-mastectomy. This sub-theme related to how undergoing mastectomy had affected the study participants’ ability to resume normal work or their usual livelihoods after the procedure. From the findings, majority of the study participants, indeed, acknowledged that they were unable to resume their normal work or their usual livelihood earning activities following the mastectomy. Particularly, most of the participants indicated that they were unable to do much physical work. Most also indicated that they had to leave their jobs as they were unable to continue with working post-mastectomy. The participants attributed their inability to resume normal work to their diminished physical strength and functioning following the mastectomy. It was therefore evident that the participants’ work life was adversely impacted post-mastectomy. This is illustrated in the ensuing verbatim excerpts;

“... Yes I cannot do farm work, as I feel weak and have a problem with this affected hand, ... so I am being assisted by my children and relatives and my husband. My children are doing the roles I was doing, helping with house chores and cooking ..., even my husband has to cook which he was not doing before” (P6)

“My work life is affected because after surgery I realized that one side of my hand (the affected hand) cannot lift up objects and cannot work, then it became weak, immediately after surgery and some healing I commenced chemotherapy, then my body lost it’s strength, so I just stay at home” (P4)

“Initially, immediately after the surgery, I was okay and I could do things by my own. After a short while, though, my body began swelling, I would feel weak and unable to walk, unable to wash own clothes or even cook for myself, it is at that point that my daughter took me in, I now stay with her and she looks after me, as there is no much that I am able to do for myself.” (P5)

“My working has been affected because this hand (*lifts the said hand*) is in pain, not like in the past, so when I lift it up, it pains a lot, there is not much then that I am to do.” (P2)

“... like I told you, I am a farmer, but now I no longer engage in farm work as I used to. Even my husband work as a butcher is often interrupted, as he has to bring me to hospital every so often, so he keeps closing his business too, so everything has been affected” (P8)

“... the surgery has made my body to be very weak, ... I now just stay, I am not able to work as I used to. I was running a business, but closed it down, as I could no longer work. It is like my life has come to a stand still... ” (P1)

“... My body cannot be the same as it was before, I am not able to engage in a lot of work, particularly physical work, and I cannot walk long distances, so basically I am grounded ...” (P9)

However, one of the participants indicated that their work life had not been disrupted following mastectomy which she attributed to having an understanding employer that allowed her time off work to recover from the illness. This is illustrated in the following verbatim excerpt;

“My working life has not been affected in any way, because where I work my employer, one of the County Governments, has a very good understanding, so they have given me time off for healing, ... so I have not gone back to work and I am still on full salary and nobody is harassing me.” (P7)

### 4.3.3 Disrupted sexual life

Disrupted sexual life emerged as the third sub-theme of diminished physical functioning among the study participants post-mastectomy. From the findings, majority of the study participants shared the view that their sexual life had been severely affected in the post-mastectomy period, with most indicating that they were no longer able to have normal sexual relations and activity with their marital partners. From the findings, a significant proportion of the participants shared that they experienced significantly reduced desire for sexual intimacy, while others indicated that they no longer had any desire for sex. It was therefore evident that the participants' sexual life had been seriously eroded post-mastectomy. This is elucidated in the ensuing verbatim excerpts;

“... my marital life with my spouse is completely broken, he is isolated from me, I no longer have any desire for sex, and if he asks for it, I tell him, me I do not want it. Though we are old now, but I can not help him in that, the desire is completely not there on my part..” (P2)

“... my husband understood my circumstances, and though I was unable to meet his sexual needs, he stayed with me, he did not leave me, we continued with our life, and I am thankful to him for that...” (P3)

“After getting this disease and starting the treatment I decided to disengage myself from sexual issues, ... now you see since my body is sick and I am also feeling ashamed because I do not have one breast, I decided to stay by myself because I have children, so it is better I take care of my children” (P4)

“... that thing (*meaning sexual relations with the partner*) is impossible. you have no feelings for it because of many thoughts and possibly due to the effects of treatment. It is actually not even in your thoughts and it also feels burdening, but my husband has been very understanding and faithful, let us leave it at that ...” (P8)

“... Yes, we relate well (*referring to her relationship with her husband*) but now you see, you know being a lady, there are things you cannot satisfy him, so you just ignore, it does not bother me. I have no problem if he has sexual relations out there now, because there is nothing I can do to change the situation.” (P7)

“...You know I have not even healed properly and I am not able to do any physical work, so I cannot even engage in any sexual relations at the moment, may be gradually with time, but I do not know how things will turn out.” (P9)

“... about the marital status, mine is not there because my husband passed on, but the thing is right now I am quite scared to be engaged to someone, I would like to be married again because he passed on in 2013, but now I am scared, I can not pray for a husband, because I have fear that when he comes he will realize I do not have one breast, and he could reject me.” (P10)

However, one of the participants indicated that her sexual life had not been altered by the mastectomy experience and that her sex life within her marriage remained well and active, as depicted in this ensuing verbatim excerpt;

“Sometimes he (meaning the husband) is quite afraid during our sexual union. Initially he was afraid but now with time he is quite okay and feels very free during our union, ... so the flavor of our love is still alive and our love life is still very active” (P6)

#### **4.4 Psychological experiences and perspectives of the women post-mastectomy**

The study explored the psychological experiences and perspectives of the study participants post-mastectomy. In this study, psychological experiences and perspectives were defined as the aggregation of mental feelings, thoughts and emotions that the women experienced after undergoing mastectomy. It thus aimed to find out how undergoing mastectomy affected the women’s general mental wellbeing. Therefore, a review of the women’s psychological experiences and perspectives post-mastectomy explored the participants’ views regarding how undergoing mastectomy had affected them psychologically, that is, how their personal thoughts, feelings and emotions were impacted by undergoing mastectomy. Psychological experiences and perspectives in the context of breast cancer patients, according to Anim-Sampong et al. (2021), Zhu and Zou (2021) and Twahir et al. (2021), signifies the women’s mental wellbeing following treatment and therefore denotes how their individual thoughts, emotions and feelings are impacted by the treatment received.

The primary focus of discussions with the participants was on how mastectomy had affected them psychologically/mentally. Each transcript was scrutinized several times to identify key phrases which were then assigned appropriate codes. The phrases were then reduced and subsequently grouped on the basis of similarity in thoughts, ideas and meaning into clusters. The clusters were then organized into concepts which in turn were grouped into themes and sub-themes. The main theme and sub-themes in

relation to the participants' psychological experiences and perspectives post-mastectomy are summarized in Table 4.4.

**Table 4.4: Theme and sub-themes on participants' psychological experiences and perspectives post-mastectomy**

<b>Research objective</b>	<b>Theme and sub-themes</b>	<b>Definition of the theme &amp; descriptors</b>
To explore psychological experiences and perspectives of individuals with breast cancer who have undergone mastectomy at Kenyatta National Hospital	<p>Mental distress</p> <p><i>Sub themes</i></p> <p>Anxiety and stress</p> <p>Hopelessness with life</p> <p>Low self esteem</p>	<p><i>Mental distress</i> denoted experiences of mental anguish or adverse thoughts among the participants attributable to undergoing mastectomy.</p> <p><i>Anxiety and stress</i> denoted feelings of constant fear, worry and strain that the women experienced post-mastectomy.</p> <p><i>Hopelessness with life</i> denoted feelings of giving up, despondency and futility with living that the women experienced post-mastectomy</p> <p><i>Low self esteem</i> denoted feelings of lack of or low self appreciation that the women experienced post-mastectomy</p>

During the discussions with the study participants, it emerged that mental distress constituted the most common psychological experience among the study participants post-mastectomy. From the findings, majority of the study participants explained that the whole experience of battling breast cancer and losing one of their breasts following mastectomy left them scarred. Most of the participants also acknowledged that they experienced a whole lot of psychological turmoil post-mastectomy characterized by feelings such as anxiety and stress, feeling depressed, hopelessness with life, loneliness, fear of rejection, confusion and low self esteem. In general, the participants concurred that their mental wellbeing suffered from the whole experience of the illness and undergoing mastectomy. Three sub-themes emerged that related to how undergoing the mastectomy had affected the participants psychologically. These were experiences of anxiety and stress; experiences of hopelessness with life and

experiences of low self esteem. The three sub-themes are outlined in the following subsections.

#### **4.4.1 Anxiety and stress**

One of the psychological experiences among the study participants post-mastectomy was feelings of anxiety and stress. From the findings, most of the participants indicated that they suffered anxiety and stress as a result of the cancer diagnosis as well as a result of losing the affected breast in the mastectomy procedure. From the findings, it was apparent that being diagnosed with breast cancer was a shocking experience for majority of the study participants with mastectomy being a difficult decision for them to accept but which was necessary if they wanted to live. The study participants unanimously accepted that they experienced high levels of anxiety and stress upon being told that they had breast cancer and that they would have to undergo mastectomy as treatment and that these feelings of worry and stress persists post-mastectomy. This is illustrated in the following verbatim excerpts;

“... I was very confused and stressed when I was told I needed to undergo surgery to remove my breast due to the cancer. I wondered how will I live without my breast, ... so the problem was there even after mastectomy, it was too hard for me to leave the hospital, how do I go back home without my breast and I came with my two breasts, I was extremely stressed with this...” (P7)

“I have been affected psychologically, the fact that I have cancer and when I was told about mastectomy, I asked myself how will it be? I became stressed and depressed and asked God not to allow the removal of my breast; afterwards I was a bit relieved.” (P4)

“first, I was very shocked and confused (*referring to when she was informed that she had breast cancer*), ... I did not believe that I was sick. It took time for me to accept, but I was very nervous and stressed up, it took lots of counselling for me to finally accept.” (P8)

“I had no otherwise but to consent for the removal of my breast as advised by the doctors, but deep within I was deeply worried, anxious and stressed over the whole thing as one must think about what is happening to them, ... but now I do not think much, instead I am very grateful to God for life because I am not the only one affected by this disease, when I go the hospital, I see many people affected including those who are younger, so I just thank God.” (P9)

“... yes, I have suffered depression and anxiety as a result of this (*referring to mastectomy*). You have that spirit of rejection and loneliness, you do not want to bother People, yeah, you keep to yourself, it is like isolating yourself and



you are comfortable with it... you isolate yourself because you want to listen to yourself and because you do not want to hurt someone.” (P10)

“... all this does affect me mentally because you keep wondering how it will all end, it is very difficult and stressing, but I have hope it will end well, God wiling.” (P5)

“... there is a lot of mental torment with this illness, you think, you get headaches, but still you can not stop thinking, all I do is to pray that God heals me.” (P1)

“I was shocked by the bad news the doctor gave me, I got quite shocked and confused to the extent that instead of taking the right vehicle going home, I took transport going the wrong direction. I tell you I had seen much trouble at that point” (P3)

“I was very angry, I asked myself, now what is this? What is this coming to me? So I was very upset and stressed up initially, but with time, I came to accept as I had no other choice.” (P2)

#### **4.4.2 Hopelessness with life**

Losing hope with life also emerged as one of the leading psychological experiences that the study participants had post-mastectomy. From the findings, a significant number of the participants indicated that they were overwhelmed with feelings of hopelessness from time to time in their journey of treatment for breast cancer including post-mastectomy which they attributed to the rigours of the treatment and the significant adverse effects of the illness to the different facets of their lives. Hence, it was evident that loss of hope for life, post-mastectomy, was a notable psychological experience among some of the study participants, as is demonstrated in these ensuing verbatim excerpts;

“... it affects your mind, sometimes you feel you do not want to live any longer, you just wish it all comes to an end and you are gone. You feel tired with life ...” (P2)

“... this is one long journey my dear, initially, I was very scared and wondered how this would end. Not once, I have had thoughts that my life should just come to an end. The treatment, the stigma from some people, it is all too much sometimes... but I have hope and faith, I will get healed, God above all in everything...” (P5)

“I have come to realize that men are weak, I am the one who is sick but still guides the family and still encourages the man (*meaning her husband*), for him he sees ‘death’, ... he is giving up, it reaches a time I am the one encouraging him. Initially, when we started this journey, he was strong but

now he is giving up, he is feeling sorry saying my wife is so sick and yet I cannot do anything for her ...” (P7)

“I was very shocked to learn that I would lose my breast. I thought, if the breast gets removed, will I just die, what will I do now, even my husband was initially hesitant about the procedure. It is only after being counselled for some time that he and I accepted, you know, it is not easy... it takes lot of strength and courage. So, sometimes I despair to fight on, but have to...” (P8)

#### **4.4.3 Low self esteem**

Low self esteem emerged as the third subtheme of mental distress within the psychological experiences and perspectives of the study participants post-mastectomy. Low self esteem reflected the feelings of low confidence or low self worth among the study participants after undergoing mastectomy. From the findings, a significant proportion of the participants indicated that they battled with the feelings of low self esteem following the removal of the affected breast as part of treatment they received. This could possibly be due to the great significance and emphasis that women place on their physical appearance, body image and personal beauty which in turn are unfavourably impacted by the loss of the removed breast in turn breeding feelings of low self appreciation among the affected women. This is demonstrated by the following verbatim excerpts;

“The first time to be told about mastectomy, I felt very bad and ashamed because I thought people will laugh at me having only one breast, but later on I was counselled by other people and accepted to have the surgery, first I was talked to by my sister, then a friend and later on my mother... they encouraged me to have the surgery in order to get well...” (P4)

“... I keep wondering how my friends will treat me, you know our area here is quite remote and people can be scared if they know I do not have a breast, so sometimes I cover the affected breast so that people think I have my breast. I normally stay at home, those who want to see me will see me at home and I do not allow them to ask any questions, sometimes I feel sorrowful, but I just comfort myself.” (P6)

“... it is hard to feel good about yourself as a woman once you lose a breast, isn't it; may be when a visitor comes to the house, the first thing you do is to run to the bedroom to wear a bra so that she or he will not see the weakness in you, and when you are going somewhere you just feel, it hurts when you see people are jovial but internally there is something telling you that you are not normal. So you go like you want to stand before people but something tells you not now, you are not complete. At times when the breast is removed, and you try to explain yourself, someone will take it like you have the strength,

(*you know*) they don't know that inside you there is something missing which is very important, so it has affected me a lot, a lot" (P10)

"... you cannot have the same confidence as before. It is not possible; you cannot be the same person. Even when you leave the hospital or when at home and you go somewhere, you keep wondering, oh my God, what will I say? What will I say? You feel inadequate in some way; so it affects you a lot and takes time before one can accept." (P8)

"I cannot say that I am the same person I was before the surgery, so it has affected me a lot. I wondered if I have grown old or what? Being old, I have no much to say now; that female enthusiasm is all lost in me..." (P2)

#### **4.5 Sociological experiences and perspectives of the women post-mastectomy**

The study also explored the sociological experiences and perspectives of the study participants post-mastectomy. In this study, sociological experiences and perspectives were defined as the nature of social relations and interactions that the women had with other people at family and community levels after undergoing mastectomy. It thus signified how the women's social life had been impacted post-mastectomy. Therefore, a review of the women's sociological experiences and perspectives post-mastectomy explored the participants' views regarding how undergoing mastectomy had affected their social life, that is social interactions with other members of the family and the larger community as espoused by Gichuru et al. (2020) and Lundberg et al. (2022).

The primary focus of discussions with the participants was on how mastectomy had affected their social life (relations with others). Each transcript was scrutinized several times to identify key phrases which were then assigned appropriate codes. The phrases were then reduced and subsequently grouped on the basis of similarity in thoughts, ideas and meaning into clusters. The clusters were then organized into concepts which in turn were grouped into themes and sub-themes. The main theme and sub-themes in relation to the participants' sociological experiences and perspectives post-mastectomy are summarized in Table 4.5.

**Table 4.5: Theme and sub-themes on participants’ sociological experiences and perspectives post-mastectomy**

<b>Research objective</b>	<b>Theme and sub-themes</b>	<b>Definition of the theme &amp; descriptors</b>
To explore sociological experiences and perspectives of individuals with breast cancer who have undergone mastectomy at Kenyatta National Hospital	Social support  <i>Sub themes</i> Family support Social life	<i>Social support</i> denoted how the participants’ social relations and interactions with other people, at family and community level, had been affected by undergoing mastectomy.  <i>Family support</i> denoted nature of the study participants’ social relations with other family members post-mastectomy.  <i>Social life</i> denoted the study participants’ social relations with other members of their communities such as friends, neighbours, and colleagues at work, women groups and church among others, post-mastectomy

Based on discussions held with the study participants regarding their sociological experiences and perspectives post-mastectomy, *social support* emerged as their most common social experience hence becoming the overarching theme. Social support represented the study participants’ views regarding how undergoing mastectomy had affected their social relations and interactions within their families and at the community level. This theme therefore illuminated the impact of the breast cancer diagnosis and undergoing mastectomy on the social life of the study participants as self-reported. The two subthemes that emerged under this theme were *family support* representing the study participants’ social relations with other family members, post-mastectomy and *social life* which represented the study participants’ social relations with other members of their communities such as friends, neighbours, and colleagues at work, women groups and church among others, post-mastectomy. The two sub-themes are described in the following subsections.

#### **4.5.1 Family support**

This subtheme reflected the nature of social relations and interactions that the study participants had with other family members post-mastectomy. It also reflected the

kind of support that the study participants received from family members in the course of treatment for breast cancer including in the period after undergoing mastectomy. From the findings, it was evident that family support, financial and non-financial including social, emotional and psychological, was instrumental and had a positive influence on the coping against the effects of the disease among majority of the study participants. The findings therefore signified the important role that support from family served in aiding the participants to better deal and withstand effects of their diagnosis and its treatment. This is illustrated in the following verbatim quotes;

“...Yes, my family really helps me so much. You know I am the first born but you feel the care they give you is like you are the last born, even if you tell them you are healed, they feel you are not well, so any time you meet, they will ask how are you doing? in a very caring way. My children also keep asking even if they are away, how are you doing mum? so you see even their mind is tortured because they are not there to see how you are; so they will say ‘don’t lie to me mum, how are you? Are you okay?’” (P10)

“... there are times my NHIF gets exhausted, and it cannot pay any further, so you need to have some cash to boost it. My family and friends have on many occasions stepped in to help us financially. I would say, my husband, my parents, sisters, brothers, these have truly stood with me all through. They are a strong pillar in my life.” (P8)

“...my family gives me a 100% support, even the time they realized that the disease has spread, we organized for a meeting with all of them with the doctor, they all came and we talked and talked, with the doctor updating them about my condition and telling them what to do. Even with my husband, we relate very well, so I would say I have strong family support.” (P7)

“... yes my husband is aware of my feelings, he seems comfortable, you know if he thinks too much, he will get sick. For the children, yes, they understand how I feel. I tell them, even my eldest son accompanies me to KNH for treatment, (*but now he is not around because he got employed*), but he knows mama is getting treatment. My other family members, yes, they support me, morally and financially, for instance, recently we required money for treatment, they quickly raised the money and gave me support, some of them even buy sugar and flour to support me and the children, all are really good to me and my family.” (P6)

“... when I was no longer able to do things for myself, it is my daughter who came and told me now you can not stay on your own. So, I now stay with her and she takes care of me. It is however not easy on her as she has three little children in school, so it is a struggle but she is very kind to me.” (P5)

“My family has given me great support from the time I got ill, they have shown me real love, even the ones who were a bit distant have come very

close to me, they are supporting me right at the hospital, and even at home. We bond together, people come from different places to come and see me. My family even contributed money for my daughter to continue with schooling, at a time when I was very sick, so it has been very supportive.” (P4)

“... my family have supported me all along, they said I should go for surgery and told me to carry on with medications. I get along with them very well and do help where they can.” (P3)

“I feel okay, I do not have pain, I do not have any problems personally, just eating and eating well. My children have truly stood with me and help me out all the time when I am in need, so I am good.” (P2)

“... lets say, like my family, where I came from, where I was born, they do support me a lot and where I am married, they also support me a lot. Support like of food items, they bring that to me, it is only things like paying rent where it is me who takes care of such... but in all both sides of the family have been very supportive.” (P1)

However, one of the participants indicated that she was not being adequately supported by her family as demonstrated in the ensuing verbatim excerpt;

“... yes, they (*referring to her family members*) know, this is not something you can hide from the family. Sometimes I spend nights at the hospital, this way they must know... (*responding to whether the family stands with her during the illness*) my family members come and help me with the house work and with washing of our clothes... but anything involving a lot of money makes some family members keep off” (P9)

#### **4.5.2 Social life**

Social life as a sub-theme reflected the nature of social relations and interactions that the study participants had with other members of their communities post-mastectomy. It also reflected the kind of support that the study participants received from other members of their communities such as friends, neighbours, fellow women in their women groups, members of their church, among others, post-mastectomy. This also included how the study participants were treated by these members of their community, post-mastectomy. From the findings, most of the study participants pointed that the support they received from friends and fellow community members was positive and helpful. This is illustrated in the following verbatim excerpts;

“... yes I am an active member and actively participate in church functions because I have seen God giving me a second chance to live, so my first priority is to serve God so that I can encourage others.” (P10)

“... the church has been very supportive to me. They have been coming to pray with us as a family, sometimes even the entire church comes, other times it is the youth for the sake of my children, to just make sure that my children are okay. Other times pastors from other churches also come and join us in prayers and pray for us, it helps a lot.” (P8)

“... yes, especially the church, they are also there and have offered us lots of spiritual support, ... but with friends there are things I used to do and I can not do them anymore, especially I used to participate in games, so now they call me, ‘*where are you?*’ but now I can not be able, so it is not easy, but I can not blame anyone for it.” (P7)

“... my lady friends, when they learn that I have undergone mastectomy, they talk to me and say that I do not even look like someone who is sick. They are good because they encourage me and help me not to think so much about the illness I have as we chat about general things together.” (P2)

“Let me say, like the women with whom we are in the same women’s group, they have not deserted me, they do come to visit me. Also my church’s group, they also come to pray together with me, so I continue with both groups even if I no longer do the usual contributions that we make, but I still move together with them...” (P1)

However, some of the participants indicated that they had experienced unfavourable treatment or lack of support from some of the community members, especially in the form of social isolation and gossiping about their condition by their friends which upset the participants, as shown in the ensuing verbatim excerpt;

“Friends, wah! Maybe you pray that God gives you one genuine one. It is your friends who go gossiping bad things about you out there, like, ‘*there, there she goes, her breast got cut off, I do not know what she will do now; her husband will now marry again*’. Well, not all (*meaning the friends*) are bad, but most will laugh at you; but some, who are few, will stand with you and will be genuinely empathetic, the few then becomes your true friends and companions.” (P8)

“... friends will leave you when you get sick. They will leave you, because they think you are looking for money but this does not bother me. God is the only one to enable one to be alive, this is not a death sentence even those who are not sick may die and leave the one who is sick alive.” (P9)

“It has affected me because they gossip about me, my friends come to see me once and never return back again. The ones who come to see me even those who used to visit me are not visiting me anymore, and the ones who know it (*referring to her having undergone mastectomy*) tell the others that I do not have my breast.” (P6)

“... they all left me (*referring to the friends she had before she got sick*) since I got sick, even calling me on phone, they do not, they vanished ... for the church, rarely I am able to go to church as most of the times I feel my body is not good, I feel I just want to rest.” (P5)

#### **4.6 Rehabilitation support systems available to the women post-mastectomy**

The study sought to describe the participants' views regarding the rehabilitation support systems that were available to individuals with breast cancer post-mastectomy. In this study, rehabilitation support systems were defined as forms of support which were available to individuals with breast cancer to help them better cope with the health condition and their life post-mastectomy. Therefore, a review of the rehabilitation support systems explored the participants' views regarding the various forms of support that were there to help improve their quality of life post-mastectomy. Michael et al. (2022) and Soleimani et al. (2022) shared similar explanations of rehabilitation support systems, in relation to persons with breast cancer, as being the diverse forms of support, treatment or otherwise, offered to individuals with breast cancer, to improve their life's quality prior to, during and following mastectomy.

The primary focus of discussions with the participants was to identify their views regarding the kinds of rehabilitation support systems that existed for patients with breast cancer post-mastectomy. Each transcript was scrutinized several times to identify key phrases which were then assigned appropriate codes. The phrases were then reduced and subsequently grouped on the basis of similarity in thoughts, ideas and meaning into clusters. The clusters were then organized into concepts which in turn were grouped into themes and sub-themes. The main theme and sub-themes in relation to the rehabilitation support systems available to the participants post-mastectomy are summarized in Table 4.6.



**Table 4.6: Theme and sub-themes on rehabilitation support systems available to the participants post-mastectomy**

Research objective	Theme and sub-themes
To describe rehabilitation support systems available to individuals with breast cancer post-mastectomy at Kenyatta National Hospital	Psychosocial support programs <i>Sub themes</i> Counselling Group therapy Breast reconstructive surgery
<p><b>Definition of the theme &amp; descriptors</b></p> <p><i>Psychosocial support programs</i> denoted the diverse forms of support systems available to persons with breast cancer post-mastectomy to help improve their life's quality.</p> <p><i>Counselling</i> denoted varied forms of advice, guidance and support offered to the participants during their treatment.</p> <p><i>Group therapy</i> denoted kinds of support groups available for patients with breast cancer where they met to discuss their experiences with the ailment and treatments being received as well as share gained insights while, at the same time, encouraging and supporting each other.</p> <p><i>Breast reconstructive surgery</i> denoted a form of surgery in which women who have undergone mastectomy are fitted with an artificial breast to replace the removed one.</p>	

Psychosocial support programs emerged as the overarching theme in discussions with the participants regarding their views of the rehabilitation support systems available to persons with breast cancer post-mastectomy. From the findings, majority of the study participants acknowledged being aware of the existence of counselling and group therapy as interventions to help persons with breast cancer cope with the illness and its associated treatments. Few, however, of the study participants had heard of breast reconstructive surgery as a rehabilitation intervention available to women who had undergone mastectomy. According to the findings, most of the participants were in agreement that they had received or utilized two of the three psychosocial interventions (counselling and group therapy) which in turn helped them cope better with the disease and also helped them have a more positive outlook of their lives the illness notwithstanding. These psychosocial support programs offered an opportunity and forum for the patients with breast cancer to share their experiences in the journey of cancer treatment, to learn more effective coping mechanisms and even to learn

more about the disease and treatment(s) received. The three subthemes are described in the ensuing subsections.

#### **4.3.4.1 Counselling**

Counselling as a subtheme reflected one of the forms of psychosocial support provided to the study participants post-mastectomy. Counselling represented various forms of advice, guidance and support offered to the study participants during their treatment. From the findings, the study participants were in agreement that the counselling they received was indeed helpful in enabling them to accept and cope with the cancer diagnosis as well as the mastectomy treatment. The participants indicated that much of the counselling focused on bolstering their mental and emotional strength in the face of the cancer diagnosis and treatment and equipping them with tips and skills to better cope with the effects of the illness. The counselling, according to the participants, was provided by health care workers mainly counsellors and nurses and to a lesser degree by physicians in the cancer care centres that they attended for treatment. However, some of the participants also got counselling from non-hospital settings such as the church or at home by members of their communities such as their church pastors and visiting friends. Most of the participants, however, expressed the view that the counselling offered was insufficient and that more counselling should be given over the course of the treatment.

This is evident in the following verbatim excerpts;

“... I only received counselling at the point of being told that I had cancer at clinic 24. Yes, it (*referring to counselling received*) was helpful, though I was very shocked at that time. It would be good if I would receive additional counselling as I progress with treatment.” (P1)

“... yes, I received counseling in one of the hospitals, there are people who came and counselled me and even gave me a book on counselling to be reading. I have the book at home. I was counselled both before and after the mastectomy. Also, I was counselled by another woman we met during a hospital visit in one of the county referral hospitals. She really gave me hope and encouraged me. She told me ‘*this is my seventh year since I underwent mastectomy*’ and advised me that the only bad thing is thinking so much about the illness because that brings other problems. So, she truly gave me hope.” (P2)

“Yes, I was counselled while in hospital here. I was given instructions of what to do, I was given a book to read and dietary advice on what types of food to eat, lots of vegetables, white meats like chicken, fish, eggs, to avoid red meat but eat very little of the meat. So, yeah, i would say I was counselled.” (P3)

“Yes, while in the hospital, the doctors were going round and talking to us, in case they found one depressed, they would talk to you. Actually, when I came to the clinic for the first time before being diagnosed with cancer, I was counselled one on one by a counselor. I just went in alone and talked to the counsellor, and we discussed everything including chemo and its complications. I did not, however, receive any counselling after mastectomy.” (P4)

“yes, counselling, we (*referring to herself and fellow patients*) got it here. We were informed that the chemotherapy we received, prior to the surgery, was to shrink the tumor to allow for mastectomy, something like that. It is always helpful to get someone to talk to you, especially a professional counsellor, to give you the heart to continue pushing...” (P5)

“I was counselled here in hospital; they also gave me a book which I am continuing to read. Following the counselling, I am adjusting myself to my current status, I am aware of what is going to happen, in case my hair is falling off and I am losing weight, I am fully aware. So, yes, the counselling has helped me to cope.” (P6)

“yes, I have been counselled, especially my doctor (*name withheld*) sometimes I book an appointment with him, he tells me to sit here, and says ‘*you, your head is the one that is sick you are not sick*’ and then something about him even if I call him, whatever the time he finds I had called him, he will always call back, he has been there for me in such a big way; for him he does not work for money not everything he does for me, I have to give him money, he is that kind” (P7)

“Yes, I was counselled by a young man in one of the clinics here and yes, I was satisfied with the counselling offered.” (P9)

“The first counselling I had it here at the hospital when I was told I have breast cancer then the second one was in the church. I have been going to church to pray with my pastor so that I get encouraged, yeah.” (P10)

#### **4.3.4.2 Group therapy**

Group therapy was another form of psychosocial support that was available to the study participants post-mastectomy. Group therapy represented various kinds of support groups available for patients with cancer where they meet to discuss their experiences with the ailment and treatments being received as well as share gained insights while, at the same time, encouraging and supporting each other. From the

findings, only few of the study participants indicated being aware of group therapy or even taking part in it. Most of the study participants indicated that they were not aware of the existence of this form of psychosocial intervention. However, once they were informed about group therapy and its essence by the researcher, most indicated willingness to join and take part. This is demonstrated in the following verbatim excerpts;

“... that one (*referring to the group therapy*) I have tried to create time for it, it has helped me so much, I normally ask the social worker to invite me. You know I am alone in the house, without my children who are grown. I do not socialize with others because they will see my imbalance, so what I normally do, I like joining the group in order to get encouraged. I was informed about it after finishing chemotherapy and radiotherapy, so I went and then I felt in my spirit that I would like to join a group because I was told that there are certain programs and sharing of experiences, so I requested to be informed where they are and when, so that is how I came to know of and join the group.” (P10)

“... group therapies are very important. You know, you are able to share your own experiences, this one says hers, another one narrates hers and yourself too get an opportunity to say yours, and that way we encourage each other, so they are important and should continue.” (P8)

“Yes, I have heard that cancer people are have meetings, where the share their experiences, but that time I was being given Chemo, and Yes I would be interested to join such groups...” (P9)

“... yes, I am a member of such a group in my local hospital. we even have calendar for our meeting schedule for every month in the hospital. they are also some ladies near to our church who also teach other people about cancer. We have also started another group where we will be meeting twice every month and we shall be sharing in our mother tongue. Yes, I do like these groups very much; the shared experiences make you feel you are not alone in this thing, so they are very helpful.” (P2)

“I came to learn of group therapy from other ladies with whom we were attending treatment here in hospital; so, they told me there is a meeting, after the clinic, so I should wait and because personally I love such things, I waited and participated. I learnt lots of good things from that group therapy. I listened to testimonies from other women of how they have been able to move on with their life despite having cancer, that having cancer did not mean you will die, and that all that was important is to give yourself hope and know that God is there and He heals, that to God it does not matter you are in which stage of the cancer,... all these really gave me hope and I felt encouraged” (P1)

“I have never heard about that (that is, group therapy). I have never been informed about that by anybody. Yes, if there are such groups, sure I would

like to join. It would be good to meet with other people who have similar problems, as I have, and share our experiences.” (P4)

“No, I have never been informed about the existence of group therapy. Yes if I am invited, I can attend the future meetings” (P3)

“No, I have never been informed about the support groups, but I have heard there is support group here and people are meeting regularly. Honestly, I do not know... sure, next time, in case I will be in Nairobi, I can attend” (P6)

“She (*meaning her mum and who is a breast cancer survivor*) normally tells me about it but now I am not ready. Sure, maybe in the future I could join these groups, but the positive ones. ” (P7)

#### **4.3.4.3 Breast reconstructive surgery**

Breast reconstructive surgery was the third sub-theme under psychosocial support programs that were available to the study participants post-mastectomy. Breast reconstructive surgery represented a form of rehabilitative support available to women with breast cancer who had undergone mastectomy in which the women would undergo another surgery to be fit with an artificial breast to replace the removed one. From the findings, only few of the study participants indicated as having heard or being aware of breast reconstructive surgery. There was split opinion as to whether the participants would be open to undergo a breast reconstructive surgery with some indicating that they would be willing to have it done while others were completely opposed to the idea mainly due to the fear of undergoing another surgery. For the participants that expressed openness to undergo breast reconstructive surgery, the high cost of the procedure in the country was a major deterrence to their consideration for undergoing the procedure. These views about breast reconstructive surgery, as expressed by the study participants, are demonstrated in the following verbatim excerpts;

“ Yes, I have heard about it (*referring to breast reconstructive surgery*) and I would love to have it but I was told it is very expensive and I cannot afford,... I had requested the doctor to tell me about the treatment and types of surgery available, so he mentioned it but the cost was too high (*he said it requires about about Kshs. 400,000*), I can hardly afford it and so I did not pursue the idea further. I would however be interested if it is affordable.” (P10)

“I have heard but I have never seen any. I saw one yesterday from one of the ladies who showed me hers (*referring to prosthesis*). I would like to have one

because currently I have packed some cut clothes in that place. For me I just pack clothes but if I see a good one, I might want one.” (P9)

“... what, you are taking to theatre? (*the researcher elaborates to her that it is a surgical procedure done in a theatre*) that one no, a big no. Things to do with going back to the theatre, I do not like to hear them, better I stay as I am.” (P8)

“(in reference to breast reconstructive surgery) I am not interested. Whatever I have improvised, I feel comfortable with it. As I was going home I got a very good doctor, a man who advised me on what to do, use a fiber, make the sponge and fix into the brassiere, that is what I use so even if I move up and down I am okay. I am comfortable” (P7)

“I have always wanted to know but I did not know whom to ask and Yes I would like to have it done on me. At the moment, I am using a sponge which I have fitted on the brassier. If I get such (*referring to a prosthesis*) I will be happy because sometimes I forget and my dress looks unbalanced, one side falling.” (P6)

“I have never heard of an artificial breast to replace the one removed. Well, I am not aware of it (*referring to prosthesis*) as well. I would consider anything that would help, but right now I am not yet well recovered, and my breast is inflamed so maybe at a later point once I get better.” (P5)

“Yes, I was told by the surgeon who operated me (*that is, about breast reconstructive surgery*), but I declined, I was afraid to go back to theatre. I told them weeh, I do not want to go back to theater. (*On being offered prosthesis*) I went to the hospital because I was told they were giving it out but I was told they were finished and I did not follow up.” (P4)

“No, I do not know about it (*referring to breast reconstructive surgery*). Yes, I would like to have one because it is permanent and no one would know about it. I would want to know how much it costs. Could be I may consider if I can afford it.” (P3)

“I have never heard about reconstruction of the removed breast. Why did they not tell me about it? While I would not want to undergo the surgery one, I would be happy to have the other one (*referring to prosthesis*), because every time I wear clothes, they fall on one side. I heard of the one made on brassier, and there was a lady who was to show us how to sew it during our December clinic, but she did not because of time constraints. Kindly help me get one if able (*placing a request to the researcher for help to get the prosthesis*).” (P2)

“I am hearing it (*that is, about breast reconstructive surgery*) from you for the first time; I have never been told about that. But there is woman who showed us how to sew a stretching material on the brassier (*a self made prosthesis*), so a friend of mine helped make three for me which I use interchangeably. I am very happy with it and feel comfortable. Of course, I would love it (*referring to more permanent prosthesis*)” (P1)

## **5.0: CHAPTER FIVE: DISCUSSIONS/CONCLUSIONS AND RECOMMENDATIONS**

### **5.1 Introduction**

This section highlights discussion of findings, conclusions and recommendations of the study in accordance with the identified themes and sub-themes. The study explored experiences of individuals with breast cancer post-mastectomy at Kenyatta National Hospital.

### **5.2 Discussion of Findings**

#### **5.2.1 Physiological experiences and perspectives of the women post-mastectomy**

Diminished physical strength/functioning emerged as the first overarching theme of the study. The study established that reduced physical strength/functioning constituted the most common physiological experience among the study participants post-mastectomy. From the findings, majority of the study participants indicated that they were not able to perform at the same physical level as they were prior to the mastectomy. This denoted that the physical health status of women with breast cancer declined or was adversely impacted by undergoing mastectomy. Yamani Ardakani et al. (2020) in an empirical probe of views of women with breast cancer in Iran also found that most of the women reported experiencing decline in their physical strength following mastectomy. Equally, surveyed women being treated for breast cancer did also report as experiencing increased difficulties to perform activities requiring physical effort post-mastectomy compared to their pre mastectomy period in a study by Zhu and Zou (2021). Twahir et al. (2021) in a study conducted in three African states namely Nigeria, Kenya and Ghana did cite reduced physical capacity to undertake activities requiring physical effort as being a leading real-life challenge experienced by persons with breast cancer in these countries particularly post-mastectomy.

In this study, most also indicated that they experienced low energy levels, general body weakness and that their bodies had lost its strength. In general, the participants concurred that they were no longer able to perform physically demanding tasks or

work after undergoing the mastectomy. Similarly, in a retrospective study performed among patients with breast cancer in three sub-Saharan African countries, Twahir et al. (2021) also reported diminished physical capacity and reduced ability to perform physical tasks following mastectomy relative to before undergoing the procedure among most of the surveyed patients. Gichuru et al. (2020) did also report that women who had undergone mastectomy experienced reduced physical strength and ability to perform activities requiring physical effort post-mastectomy relative to their physical status/ability before being diagnosed with breast cancer and prior to undergoing mastectomy. On their part, Iddrisu et al. (2020) did also establish that diminished physical strength including ability to perform normal activities of daily living was one of the leading lived experiences among women with breast cancer that had undergone mastectomy. This clearly illustrates that undergoing mastectomy had a perceived adverse effect on the physical health and wellbeing of persons with breast cancer.

Altered body image emerged as one of the physiological experiences and perspectives of the study participants post-mastectomy. From the findings, the study participants indicated that their body image was unfavourably affected by the mastectomy procedure due to the gap left on the removed breast. Most of the participants expressed having concerns over their body appearance owing to the distortion brought about by the missing breast. Indeed, some participants expressed disappointment and displeasure with their physical appearance owing to the loss of their breast following the mastectomy. These negative sentiments over the altered body image among the study participants can be understood given that breasts are an important intimate part of female body and carry great significance to their maternal roles, outlook as well as perceived beauty. Türk et al. (2018) also pointed that mastectomy causes greater disfigurement than other forms of surgery leading to a poorer body image and deterioration in affected women's quality of life. Particularly debilitating to body image, as argued by Yabe et al. (2021), are the alterations and the removal of the entire breast causing loss of symmetry and change in physical appearance with an adverse impact on the body image, especially on women with very high expectations of physical beauty. Similar views were expressed by Gichuru et al. (2020) who argued that it was important for the health care workers to evaluate the physical body changes after mastectomy in order to avert negative biopsychosocial functioning in the



patients. Padmalatha et al. (2021a) did also acknowledge that the disfigurement resulting from mastectomy was one of the commonly cited unfavourable physical experiences among women having breast cancer post-mastectomy.

Disrupted work life emerged as another leading physiological experience among the study participant's post-mastectomy which denoted the effects of mastectomy on the study participant's ability to resume normal work or their usual livelihoods after the procedure. From the findings, majority of the study participants, indeed, acknowledged that they were unable to resume their normal work or their usual livelihood earning activities following the mastectomy. Particularly, most of the participants indicated that they were unable to do much physical work. Most also indicated that they had to leave their jobs as they were unable to continue with working post-mastectomy. The participants attributed their inability to resume normal work to their diminished physical strength and functioning following the mastectomy. It was therefore evident that the participants' work life was adversely impacted post-mastectomy. According to Li et al. (2022) and Zhou et al. (2019), mastectomy can cause many anatomical and physiological disorders which can result in limitations in daily activities of living among affected individuals in turn jeopardizing their livelihoods. Similarly, a study by Mülkoğlu et al. (2022) revealed that mastectomy adversely affected the livelihoods of breast cancer patients through its unfavourable effects on their physical wellbeing as it usually left with diminished physical strength or functioning, which in turn decreased their ability to continue working normally. In contrast, though, no significant differences were observed in the work life status of women with breast cancer in Sweden between pre and post-mastectomy denoting that undergoing mastectomy did not significantly alter the surveyed women's ability to continue with their normal work life as established by Lundberg et al. (2022).

Another physiological experience under the theme of diminished physical functioning among the study participants post-mastectomy was disrupted sexual life. From the findings, majority of the study participants shared the view that their sexual life had been severely affected in the post-mastectomy period, with most indicating that they were no longer able to have normal sexual relations and activity with their marital partners. From the findings, a significant proportion of the participants shared that they experienced significantly reduced desire for sexual intimacy, while others

indicated that they no longer had any desire for sex. It was therefore evident that the participants' sexual life had been seriously eroded post-mastectomy. Similar views were espoused by Paterson et al. (2016) and Iddrisu, et al. (2020) who opined that, in terms of physical functioning, a negative body image perception has often been found to be associated with greater sexual difficulties which can include hot flashes, vaginal dryness, atrophic vaginitis, and decreased libido due to premature menopause. This is mostly a complication of chemotherapy and radiotherapy which can have a particularly negative effect on the sexuality of the younger woman being treated for breast cancer post mastectomy. In a survey conducted in Nigeria, Michael et al. (2022) established that in Nigeria found that six months after surgery, the survey responses revealed that 67.9% of women felt inadequate as a woman because of the mastectomy and that 79.0% experienced a decrease in the frequency of conjugal relations. Mülkoğlu et al. (2022) also espoused that sexual dysfunction resulting from undergoing mastectomy often lead to marriage discordance and marital strain ending up with dysfunctional families.

### **5.2.2 Psychological experiences and perspectives of the women post-mastectomy**

Mental distress emerged as the major theme under psychological experiences and perspectives among the study participants post-mastectomy. Its subthemes included anxiety and stress, hopelessness with life and low self esteem, a discussion on which herein follows.

One of the psychological experiences among the study participants post-mastectomy was feelings of anxiety and stress. From the findings, most of the participants indicated that they suffered anxiety and stress as a result of the cancer diagnosis as well as a result of losing the affected breast in the mastectomy procedure. From the findings, it was apparent that being diagnosed with breast cancer was a shocking experience for majority of the study participants with mastectomy being a difficult decision for them to accept but which was necessary if they wanted to live. The study participants unanimously accepted that they experienced high levels of anxiety and stress upon being told that they had breast cancer and that they would have to undergo mastectomy as treatment and that these feelings of worry and stress persists post-mastectomy. Grassi et al. (2019) also opined that most individuals will experience

some level of anxiety, fear and depression when cancer becomes part of their lives, and that people who undergo mastectomy were more likely to experience mental distress. According to Lovelace et al. (2019), poorer body image has been linked to greater overall psychological distress in patients with breast cancer and has previously been found to be associated with severe depression and anxiety. According to Padmalatha et al. (2021b), one in four women with breast cancer has symptoms of depression after simple or radical mastectomy, and both surgeries were associated with depression in women one year after surgery. Similarly, Davis et al. (2020) also reported higher levels stress and worry among women with breast cancer who had undergone mastectomy compared to those who had not gone through the procedure.

Losing hope with life also emerged as one of the leading psychological experiences that the study participants had post-mastectomy. From the findings, majority of the study participants explained that the whole experience of battling breast cancer and losing one of their breasts following mastectomy left them scarred. Further, a significant number of the participants indicated that they were overwhelmed with feelings of hopelessness from time to time in their journey of treatment for breast cancer including post-mastectomy which they attributed to the rigours of the treatment and the significant adverse effects of the illness to the different facets of their lives. Hence, it was evident that loss of hope for life, post-mastectomy, was a notable psychological experience among some of the study participants. Lovelace et al. (2019) in a similar investigation did also establish hopelessness manifested by general lack of enthusiasm over continued living as being one of the long-term psychological effects of breast cancer surgery and survivorship care. Likewise, Lundberg et al. (2022) in a study undertaken in Sweden also reported elevated levels of desperation and loss of enthusiasm with life among women diagnosed with breast cancer post-mastectomy. In a study evaluating determining factors associated with death depression in women with breast cancer, Soleimani et al. (2022) reported higher tendencies of giving up with life and general reduced enthusiasm to keep living among breast cancer patients who underwent mastectomy. They attributed this to frustrations over recurrence of cancer despite mastectomy and to the deleterious effects of the disease on the affected women's quality of life as well as adverse effects of mastectomy on their physical appearance and strength.

Low self esteem was another reported psychological experience and perspective among the study participants post-mastectomy. Low self esteem reflected the feelings of low confidence or low self worth among the study participants after undergoing mastectomy. From the findings, a significant proportion of the participants indicated that they battled with the feelings of low self esteem following the removal of the affected breast as part of treatment they received. This could possibly be due to the great significance and emphasis that women place on their physical appearance, body image and personal beauty which in turn are unfavourably impacted by the loss of the removed breast in turn breeding feelings of low self appreciation among the affected women. According to Brunet et al. (2021) who argued that body image of a woman includes the symbolic meaning and importance of her breasts. The more value attached to her breasts the more devastating effects of having a mastectomy can be. Yamani Ardakani et al. (2020) agrees noting that women who attach lots of importance to their physical beauty are more likely to experience low self esteem following the removal of the affected breast in a mastectomy procedure. Turk et al. (2018) asserted that mastectomy involves the loss of the former figure and harms the image the women make of their bodies; it is considered an attack on body image, which makes individuals feel not beautiful contributing to their low self esteem. Koçan et al. (2019) argued that, for most women, the breast means femininity, beauty, motherhood, and attraction, and is seen as an organ that perfects women's beauty. As such, Mastectomy is perceived as ruining women's femininity and beauty in turn leading them to suffer from low self esteem due to their deformed bodies. No longer feeling beautiful and discontent with one's physical appearance following mastectomy was also identified as a recurring theme among surveyed women diagnosed with breast cancer in a study by Maleki et al. (2021). This provides evidence that undergoing mastectomy did affect breast cancer women's self-esteem unfavourably.

### **5.2.3 Sociological experiences and perspectives of the women post-mastectomy**

Based on discussions held with the study participants regarding their sociological experiences and perspectives post-mastectomy, the overarching theme was social support. Social support represented the study participants' views regarding how undergoing mastectomy had affected their social relations and interactions within

their families and at the community level. This theme therefore illuminated the impact of the breast cancer diagnosis and undergoing mastectomy on the social life of the study participants. The two subthemes that emerged under this theme were family support and social life. These are as hereby discussed.

Family support emerged as one of the leading sociological experiences among the study participants post-mastectomy. Family support reflected the nature of social relations and interactions that the study participants had with other family members post-mastectomy. It also reflected the kind of support that the study participants received from family members in the course of treatment for breast cancer including in the period after undergoing mastectomy. From the findings, it was evident that family support, financial and non-financial including social, emotional and psychological, was instrumental and had a positive influence on the coping against the effects of the disease among majority of the study participants. The findings therefore signified the important role that support from family served in aiding the participants to better deal and withstand effects of their diagnosis and its treatment. Liu et al. (2022) did also outline support from family as playing a crucial role in decision-making about mastectomy amongst women having breast cancer in China. Social support from family members, as espoused by Archangelo et al. (2019), especially from close family members such as spouse, parents and siblings played an important role in coping with and recovering from breast cancer and treatments. Therefore, social support should be a key component of the management and care of breast cancer survivors. Similarly, Zhu and Zou (2021) also established support from family as being critical to women after Mastectomy especially in coping the effects of the procedure and in helping to cover roles that they were playing prior to the illness. Aprilianto et al. (2021) also pointed to the significance of family support in treatment decisions of women with breast cancer and noted that it was instrumental in better coping with the illness post-mastectomy.

The second component of the social support theme as a sociological experience among the study participants post-mastectomy was social life. Social life as a sub-theme reflected the nature of social relations and interactions that the study participants had with other members of their communities post-mastectomy. It also reflected the kind of support that the study participants received from other members

of their communities such as friends, neighbours, fellow women in their women groups, members of their church, among others, post-mastectomy. This also included how the study participants were treated by these members of their community, post-mastectomy. From the findings, most of the study participants pointed that the support they received from friends and fellow community members was positive and helpful. Vanderpuye et al. (2017) reported similar conclusions that social interactions with other members of the community including neighbours, friends and fellow church members played an important role in helping women diagnosed with breast cancer better cope with the rigours of the illness post-mastectomy. The support could take any form including financial support, words of encouragement or even helping with looking after children. Twahir et al. (2021) in an investigation of challenges faced by for patients with breast cancer in African countries also found that support from community members whether financial or psychosocial in nature was instrumental in enabling affected patients better cope with the illness. Michael et al. (2022) did also report that positive interactions between women with breast cancer and other members of the society helped these women be more positive with life. Davis et al. (2020) did also point that lack of or adverse social interactions such as social isolation, stigma, gossiping and discrimination did affect these women and their outlook of life in a negative way.

#### **5.2.4 Rehabilitation support systems available to the women post-mastectomy**

The fourth overarching theme based on discussions held with the study participants regarding rehabilitation support systems available to individuals with breast cancer post-mastectomy was psychosocial support programs. Psychosocial support programs represented a description of the rehabilitation support systems available to individuals with breast cancer post-mastectomy as reported by the study participants. Three subthemes emerged namely counselling, group therapy and breast reconstructive surgery which are hereby discussed;

Counselling as a subtheme reflected one of the forms of psychosocial support provided to the study participants post-mastectomy. Counselling represented various forms of advice, guidance and support offered to the study participants during their treatment. From the findings, the study participants were in agreement that the

counselling they received was indeed helpful in enabling them to accept and cope with the cancer diagnosis as well as the mastectomy treatment. The participants indicated that much of the counselling focused on bolstering their mental and emotional strength in the face of the cancer diagnosis and treatment and equipping them with tips and skills to better cope with the effects of the illness. The counselling, according to the participants, was provided by health care workers mainly counsellors and nurses and to a lesser degree by physicians in the cancer care centres that they attended for treatment. However, some of the participants also got counselling from non-hospital settings such as the church or at home by members of their communities such as their church pastors and visiting friends. Most of the participants, however, expressed the view that the counselling offered was insufficient and that more counselling should be given over the course of the treatment. Similar findings were also reported by Bray et al. (2022) and Lundberg et al. (2022) who also argued that counselling interventions offered in cancer care settings offered patients with breast cancer the opportunity to not only gain better insights about the illness but also to acquire skills that would enable them better manage their life in the face of the illness, its treatment and associated difficulties. According to Grassi et al. (2019), psychosocial interventions such as counselling can facilitate the adaptation of patients to the diagnosis and treatment of breast cancer.

Group therapy was another form of psychosocial support that was available to the study participants post-mastectomy. Group therapy represented various kinds of support groups available for patients with cancer where they meet to discuss their experiences with the ailment and treatments being received as well as share gained insights while, at the same time, encouraging and supporting each other. From the findings, only few of the study participants indicated being aware of group therapy or even taking part in it. Most of the study participants indicated that they were not aware of the existence of this form of psychosocial intervention. However, once they were informed about group therapy and its essence by the researcher, most indicated willingness to join and take part. In studies by Bellver-Pérez et al. (2019) and Iddrisu et al. (2020), group therapy was found to be a popular rehabilitation support intervention for women with breast cancer as it allowed them to share their insights and experiences with the disease. They added that group therapy also offered

participating women an opportunity from which they could learn from each other on how to better deal with the diverse difficulties they faced as a result of the illness. Liu et al. (2022) also acknowledged the significance of group therapy pointing that it was an effective intervention for helping patients with breast cancer better cope with the illness through offering a platform for these persons to enlighten each other through sharing own ideas, perspectives and experiences in their fight against the disease.

Breast reconstructive surgery was the third subtheme under psychosocial support programs that were available to the study participant's post-mastectomy. Breast reconstructive surgery represented a form of rehabilitative support available to women with breast cancer who had undergone mastectomy in which the women would undergo another surgery to be fit with an artificial breast to replace the removed one. From the findings, only few of the study participants indicated as having heard or being aware of breast reconstructive surgery. There was split opinion as to whether the participants would be open to undergo a breast reconstructive surgery with some indicating that they would be willing to have it done while others were completely opposed to the idea mainly due to the fear of undergoing another surgery. For the participants that expressed openness to undergo breast reconstructive surgery, the high cost of the procedure in the country was a major deterrence to their consideration for undergoing the procedure.

Likewise, in studies carried out among patients with breast cancer in select African countries, Sutter et al. (2021) and Sharma et al. (2022) also established that most of the surveyed participants were not aware of the existence of breast reconstructive surgery as a rehabilitative support intervention. However, once informed about the intervention, some participants expressed being open to the idea of undergoing breast reconstruction surgically especially if it were affordable while others outrightly declined and indicated that they would not consider it. Similar results were also reported by Vanderpuye et al. (2017) and Twahir et al. (2021), which also explored the management of breast cancer in African countries, also reported low awareness of breast reconstructive surgery among surveyed female breast cancer patients and also reported general reluctance towards the intervention among some of the women while others indicated that they would be open to receive the intervention. Fear of surgery was the major deterrence among those opposed to the intervention while the high cost



of the procedure was the major deterrence among those who indicated willingness to undergo the procedure in the aforementioned studies.

### **5.3 Conclusions**

Based on the findings of the study, the following conclusions were drawn;

There was diminished physical strength/functioning which manifested through altered body image, disrupted work life and disrupted sexual life formed the leading physiological experiences among the study participants post-mastectomy.

Mental distress which manifested through episodes of anxiety and stress, hopelessness with life and low self esteem formed the leading psychological experiences among the study participants post-mastectomy which was observed.

Social support which manifested through family support and social life formed the leading sociological experiences among the study participants post-mastectomy.

Psychosocial support programs, mainly counselling and group therapy, formed the core rehabilitation support systems available to the study participants post-mastectomy, they should be strengthened/integrated as part of care.

### **5.4 Recommendations**

#### **5.4.1 Recommendations for practice**

Health practitioners at KNH's Cancer Treatment Centre could ensure that individuals with breast cancer seen in the hospital receive adequate counselling all through the entire treatment course from the first time they are evaluated for cancer during, after mastectomy and beyond. Awareness creation on existing rehabilitation support systems and programs including group therapy, use of appropriate prosthesis and breast reconstructive surgery to individuals with breast cancer post-mastectomy could be enhanced.

#### **5.4.2 Recommendations for policy**

The physiological, psychological and sociological wellbeing, experiences and perspectives of persons with breast cancer including those who have undergone mastectomy could constitute important considerations in hospital policy regarding management and care of these patients at KNH.

#### **5.4.3 Recommendations for research**

The current study explored the experiences of individuals with breast cancer post-mastectomy at Kenyatta National Hospital. Being a single facility study, its findings may not be generalized. A wider study on the research subject involving a wider pool of individuals with breast cancer who have undergone mastectomy in the country is hereby recommended. This would allow a broader comparison and generalization of the study findings.

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## **APPENDICES**

### **Appendix 1: Participant's information statement sheet**

**Study Title:** Exploring experiences and perspectives of individuals with breast cancer post-mastectomy at Kenyatta National Hospital - a phenomenological qualitative study.

**Investigator:** Mary Akinyi Owino-Tel: 0722964061

School of Nursing Sciences

University of Nairobi

P.O Box 19676, Nairobi

#### **Introduction:**

I am a nursing student at The University of Nairobi pursuing a Master of Science Degree in Nursing (Nursing Oncology). I am conducting a study titled: **“Exploring experiences and perspectives of individuals with breast cancer post-mastectomy at Kenyatta National Hospital: a phenomenological qualitative study.”** The aim of this information sheet is to explain details about the research in order to enable you to make an informed decision regarding your participation. You are free to ask questions to clarify any of the parts of the study we will discuss in this information and consent form. The researcher will also ask you a number of questions concerning the study before you sign the consent form to determine your understanding of the information provided.

**The Purpose of the study:** The purpose of this study is to explore the experiences of individuals with Breast Cancer after undergoing mastectomy at Kenyatta National Hospital-Cancer Treatment Center. The aim is to draw on patients' experiences and perspectives. The results of the study will contribute to the development of individualized care that will promote the improvement of the quality of care offered to patients who have undergone mastectomy.

The findings from this study will fill the existing literature gaps in the context of the management of patients diagnosed with breast cancer and form the basis for developing strategies that will improve the quality of care provided to patients diagnosed with breast cancer at Kenyatta National Hospital. The findings may influence policy towards the implementation of cancer care in the country.

**Data Collection procedure:** Once you agree to participate in the research, you will be issued with the informed consent form to sign. In this study, data will be collected using a semi-structured in-depth interview guide. In the interviews, open-ended questions will be asked based on the interdependence mode of the RAM, the researcher will also ask for your permission to record the interview session as this is the main method of data collection. The interviews will be held based on the convenience of the participants in a quiet place, the interview will take about 30-45 minutes.

- I. **Risks:** There are no economic or physical risks to participating in the study. However, due to the time taken in responding to questions, you may take a longer time than usual at your clinic. Also, during the interview, some questions will require you to disclose some personal information that might trigger some negative feelings and possible anxiety. If this happens, the researcher will stop the interview and refer you to the unit counselor on duty who is part of the study team for appropriate help. This will be done within KNH policy of referring patients for counseling support. The researcher will also endeavor to spend approximately 20 minutes with you. In case there is no improvement then referral will be done within Kenyatta National Hospital approved referral policies.
- II. **Confidentiality:** Confidentiality will be maintained and the information you provide will only be used for the intended purpose of the study. Besides, your name will not be required on any forms or used during the writing of the final report thus ensuring your anonymity. All materials used during the study will be under lock and key and only the persons involved in this study will have access to them. Electronic files will be saved on a password-protected laptop.
- III. **Voluntary Participation:** Participation in this study is voluntary. Refusal to take part will not attract any penalty. You retain the right to withdraw from the study without any consequences.

- IV. the participants and non-participants will be treated equally and with the utmost respect. Nevertheless, the outcomes will assist in policy formulation and improvement of current policies that are related to breast cancer care. Further, the study will help in You are free not to answer any questions during the interview.
- V. Compensation: No benefits in terms of monetary or favoritism will be provided. All identifying the best strategies for ensuring the quality of care of patients after mastectomy is improved. In addition, the study findings will be shared with other stakeholders in scientific conferences, peer review journals and the hospital.
- VI. **Conflict of interest:** The researcher confirms that there is no conflict of interest.

**Consent form**

I hereby consent to participate in this study. The researcher has explained the nature of the research, benefits and potential risks explained to me. I have understood that my participation in the study is voluntary and the decision to take part or not will not affect my plan of care at this facility in any way whatsoever. I may also opt to discontinue my participation in the study at any stage without any consequences. I have also been assured that my personal identification data will be kept private and confidential. I have ensured that all my concerns that may affect my participation in the study have been adequately addressed by the investigator and evaluated my understanding of the information given.

Participant’s Signature (or thumbprint) .....  
 Date.....

I confirm that I have given the participant all the information about the nature of the study and the participant has agreed to join the study voluntarily without any coercion or undue pressure.

Investigator’s Signature..... Date  
 .....

For any clarification, please contact

Investigator: Mary Akinyi Owino-Tel: 0722964061

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OR

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Ethics and Research Committee

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## **Appendix 2: Swahili version of participant information sheet/consent**

### **Karatasi ya taarifa ya mshiriki**

**Kichwa cha Utafiti:**Uchunguzi ya uzoefu na mitazamo ya watu walio na saratani ya matiti baada ya upasuaji katika Hospitali ya Kitaifa ya Kenyatta.

**Mpelelezi:** Mary Akinyi Owino-Tel: 0722964061

Shule ya Sayansi ya Uuguzi

Chuo Kikuu cha Nairobi

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**Utangulizi:** Mimi ni mwanafunzi katika Chuo Kikuu cha Nairobi nikifuata Shahada ya Uzamili ya Sayansi katika Uuguzi (Uuguzi ya Saratani). Ninafanya utafiti unaoitwa: "**Uchunguzi ya uzoefu wa taswira ya mwili ya watu walio na saratani ya matiti baada ya upasuaji wa matiti katika Hospitali ya Kitaifa ya Kenyatta: utafiti wa ubora wa phenomenological** " Madhumuni ya taarifa hii ni kukupa maelezo kuhusu utafiti ambayo yatakuwezesha kufanya uamuzi sahihi kuhusu ushiriki wako. Uko huru kuuliza maswali ili kufafanua kipengele chochote ambacho tutajadili katika taarifa hii na fomu ya idhini. Mtafiti pia atakuuliza maswali kuhusu utafiti kabla ya kusaini fomu ya idhini ili kuhakikisha ufahamu wako wa taarifa iliyotolewa.

**Madhumuni ya utafiti:**Madhumuni ya utafiti huu ni kuchunguza hali ya watu walio na Saratani ya Matiti baada ya kufanyiwa upasuaji wa upasuaji wa matiti katika Hospitali ya Kitaifa ya Kenyatta-Kituo cha Matibabu ya Saratani. Lengo ni kuteka uzoefu na mitazamo ya wagonjwa. Matokeo ya utafiti yatachangia katika ukuzaji wa utunzaji wa kibinafsi ambao utakuza uboreshaji wa ubora wa huduma inayotolewa kwa wagonjwa ambao wamepitia upasuaji wa matiti.

Matokeo ya utafiti huu yatajaza mapengo yaliyopo ya kifasihi katika muktadha wa usimamizi wa wagonjwa waliogunduliwa na saratani ya matiti na kuunda msingi wa kuandaa mikakati ambayo itaboresha ubora wa huduma zinazotolewa kwa wagonjwa waliogunduliwa na saratani ya matiti katika Hospitali ya Kitaifa ya Kenyatta. Matokeo yanaweza kuathiri sera kuelekea utekelezaji wa huduma ya saratani nchini.

**Utaratibu wa Ukusanyaji Data:** Pindi unapokubali kushiriki katika utafiti, utapewa fomu ya kibali cha kusainiwa. Katika utafiti huu, data itakusanywa kwa kutumia mwongozo wa usaili wa kina wenye muundo nusu. Katika mahojiano, maswali ya wazi yataulizwa kulingana na hali ya kutegemeana ya Roy Adaptation Model (RAM), Mtafiti pia ataomba ruhusa yako ya kurekodi kipindi cha mahojiano kwani hii ndiyo njia kuu ya ukusanyaji wa data. Mahojiano yatafanyika kwa kuzingatia urahisi wa washiriki mahali pa utulivu, mahojiano yatachukua muda wa dakika 30-45.

**i).Hatari:** Hakuna hatari za kiuchumi au kimwili kwa kushiriki katika utafiti. Hata hivyo, kutokana na muda uliochukuliwa kujibu swali, unaweza kuchukua muda mrefu kuliko kawaida katika kliniki yako. Pia wakati wa mahojiano, baadhi ya maswali yatakuhitaji ufichue taarifa fulani za kibinafsi ambazo zinaweza kusababisha hisia zisizofaa na pengine wasiwasi. Hili likitokea, watafiti watakuelekeza kwa mshauri wa hospitali. Mtafiti pia atajitahidi kutumia takriban dakika 20 na wewe na hata kuendelea kushauriana na daktari wa kisaikolojia.

**ii).Usiri:** Usiri utatunzwa na maelezo utakayotoa yatatumika tu kwa madhumuni yaliyokusudiwa ya utafiti. Kando na hilo, jina lako halitahitajika kwenye fomu zozote au kutumiwa wakati wa uchapishaji wa ripoti ya mwisho na hivyo kuhakikisha kutokujulikana kwako. Nyenzo zote zilizotumiwa wakati wa utafiti zitakuwa chini ya kufuli na ufunguo na watu wanaohusika tu katika utafiti huu ndio wataweza kuzifikia. Faili za kielektroniki zitahifadhiwa kwenye kompyuta ndogo iliyolindwa kwa nenosiri.

**iii).Ushiriki wa Hiari:** Kushiriki katika utafiti huu ni kwa hiari. Kukataa kushiriki hakutavutia adhabu yoyote. Unabaki na haki ya kujiondoa kwenye utafiti bila matokeo yoyote. Uko huru kutojibu swali lolote wakati wa mahojiano.

**iv). Fidia:** Hakuna fidia zitakazotolewa katika masuala ya fedha au upendeleo. Washiriki wote na wasio washiriki watatendewa kwa usawa na kwa heshima kubwa. Hata hivyo, matokeo yatasaidia katika uundaji wa sera na uboreshaji wa sera za sasa ambazo zinahusiana na utunzaji wa saratani ya matiti. Zaidi ya hayo, utafiti utasaidia katika kubainisha mikakati bora katika kuhakikisha huduma bora ya wagonjwa baada ya upasuaji wa kuondoa tumbo kuboreshwa. Aidha, matokeo ya utafiti yatahirikiwa

na wadau wengine katika mikutano ya kisayansi, majarida ya mapitio ya rika na hospitali.

v). **Mgongano wa kimaslahi:** Mtafiti anathibitisha kuwa hakuna mgongano wa kimaslahi.

### **Fomu ya idhini**

Ninakubali kushiriki katika utafiti huu. Nimefahamishwa kuhusu aina ya utafiti unaofanywa na kuelezwa hatari zinazoweza kutokea. Pia ninaelewa kuwa ushiriki wangu katika utafiti ni wa hiari na uamuzi wa kushiriki au kutoshiriki hautaathiri mpango wangu wa matibabu katika kituo hiki kwa njia yoyote ile. Ninaweza pia kuchagua kusitisha ushiriki wangu katika utafiti katika hatua yoyote bila maelezo au matokeo yoyote. Pia nimehakikishiwa kuwa maelezo yangu na taarifa nitakazowasilisha zitawekwa siri. Nilihakikisha kwamba wasiwasi wangu wote kuhusu ushiriki wangu katika utafiti umeshughulikiwa ipasavyo na mpelelezi na nimetathmini uelewa wangu wa taarifa iliyotolewa.

Sahihi ya Mshiriki (au alama ya kidole gumba)

.....

Ninathibitisha kuwa nimemweleza mshiriki asili ya utafiti na yaliyomo katika fomu hii ya idhini kwa undani na mshiriki amekubali kushiriki kwa hiari bila shuruti yoyote au shinikizo lisilofaa.

Saini ya Mpelelezi .....

Tarehe .....

**Kwa Ufafanuzi wowote, tafadhali wasiliana**

**Mpelelezi:** Mary Akinyi Owino-Tel: 0722964061

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### **Appendix 3: Interview guide**

**Study Title: “Exploring experiences and perspectives of individuals with breast cancer post-mastectomy at Kenyatta National Hospital: a phenomenological qualitative study.”**

#### **Introduction**

Greetings! My name is Mary Owino, I will be conducting the in-depth interview. Thank you so much for taking the time to be with us today. The interview seeks to explore the experiences of body image of individuals with Breast Cancer after undergoing mastectomy at Kenyatta National Hospital-Cancer Treatment Center. The aim is to draw on patients’ experiences and perspectives, the results of the study will contribute to the development of individualized care that will promote the improvement of the quality of care offered to patients who have undergone mastectomy.

This information will be anonymized and will be treated confidentially. You may withdraw at any time during the interview if you feel uncomfortable answering questions. The interview will be recorded for further analysis later and notes will also be taken during the interview. All recordings and notes taken will be kept safely. (Confirm that the participant gives consent to the recording before proceeding if not then don’t start the interview). The interview takes about 30-45 minutes.

Before we begin do you have any questions?

#### **Section A: Participant’s demographical data**

1. What is your age?

a) 18 - 40 years

b) 40 - 65 years

c) 65 - 75 years

d) 75 years or older

2. What is the reason for visiting the hospital today?

- a) Consultation
- b) Treatment
- c) Follow up
- d) Other (please specify).....

3. When did you undergo mastectomy?

- a) 0-6 months
- b) 6-12 months
- c) 12-24 months
- d) >24moths

4. Where do you live?

- a) Within Nairobi
- b) Outside Nairobi

5. What is your marital status?

- a. Married
- b. Single
- c. Separated
- d. Divorced
- e. Other

6. How many children do you have? .....

7. What is your level of education?

- a) Primary
- b) Secondary
- c) Tertiary
- d) Other (specify).....

8. What is your religion?

- a) Christian
- b) Muslim
- c) Hindu
- d) Other (Specify).....

9. What is your occupation? .....

10. How do you pay for your treatment and other cancer services? (May choose more than one)

- a) National health insurance (NHIF)
- b) Private health insurance
- c) Out-of-pocket
- d) Contributions from family and friends
- e) Other (specify).....

11. When were you enrolled in the cancer care clinic at KNH (specify year and month) .....

12. Which treatment(s) do you currently have or (would you) soon have? (May fill more than one if it applies to participants)

- a) Surgery

- b) Chemotherapy
- c) Radiation therapy
- d) Hormonal therapy
- e) Immunotherapy
- f) Targeted therapy

This list of questions will guide the researcher. It does not have to be adhered to systematically or completely and the participant's response will guide the questions also

**Section B: Questions and prompts**

<b>Question</b>	<b>Prompts</b>
Preliminary questions	<ol style="list-style-type: none"> <li>1. How did you get to know about mastectomy as a treatment option?</li> <li>2. What was your initial view of mastectomy as a treatment option?</li> <li>3. When and how did you decide to consider it as a treatment option?</li> </ol>
Q1. How has mastectomy affected you physically?	<ol style="list-style-type: none"> <li>4. How has your body appearance changed following mastectomy?</li> <li>5. How has mastectomy affected your: work life, normal family life, sexual life, normal physical functioning</li> <li>6. Do you experience body pain as a result of the mastectomy and how do you deal with it?</li> <li>7. At a personal level, how do you feel physically following mastectomy?</li> </ol>
Q2. How has mastectomy affected you psychologically/mentally?	<ol style="list-style-type: none"> <li>8. How has undergoing mastectomy affected your self-esteem?</li> <li>9. Have you experienced feelings of depression, anxiety or worries following the mastectomy and if</li> </ol>

	<p>so, what would you attribute it to?</p> <p>10. How has undergoing mastectomy affected your psychological well-being?</p>
<p>Q3. How has mastectomy affected your social life (or affected you socially)?</p>	<p>11. Describe your relationship with other members of the family since undergoing mastectomy?</p> <p>12. How has undergoing mastectomy affected your intimate/sexual relationship with your spouse?</p> <p>13. How has undergoing mastectomy affected your social roles (at family and community levels) (e.g. loss of identity, separation or divorce etc.)? Have there been changes? If so, what changes?</p>
<p>Q4. What kinds of rehabilitation support systems exist for patients with breast cancer post- mastectomy?</p> <p>a) Counselling</p> <p>b) Group therapy</p> <p>c)Breast reconstructive surgery</p>	<p>14. What kinds of support have you received since undergoing mastectomy (both at home &amp; hospital)? Has it been helpful and if so in which ways?</p> <p>15. What suggestions would you offer regarding kind of support needed for breast cancer patients who have undergone mastectomy?</p>
<p>Q5. Is there any other information you would like to add/share regarding your experiences and perspectives of breast cancer care?</p>	<p>If there's any, kindly go ahead ...</p> <p>If there is none then I would like to appreciate you for your participation in this study.</p>

**Tools for the interview**

Participant's consent forms

Interview guide

Audio recording device

Charging adaptor

Pens and Notebook

**Thank you**

## **Appendix 4: Swahili version of the interview guide**

**Kichwa cha utafiti:** “Uchunguzi wa uzoefu namitazamo ya watu walio na saratani ya matiti baada ya upasuaji wa matiti katika Hospitali ya Kitaifa ya Kenyatta: utafiti wa ubora wa phenomenological.”

### **Utangulizi**

Salamu! Jina langu ni Mary Owino na nitasimamia mahojiano haya. Asante sana kwa kuchukua muda kuwa nasi leo. Mahojiano hayo yanalenga kuchunguza taswira ya mwili wa watu walio na Saratani ya Matiti baada ya kufanyiwa upasuaji wa matiti katika Hospitali ya Kitaifa ya Kenyatta-Kituo cha Matibabu ya Saratani. Lengo ni kuteka uzoefu na mitazamo ya wagonjwa, matokeo ya utafiti yatumika kuendeleza huduma ya mtu binafsi ambayo itasaidia katika kuboresha ubora wa huduma.

Maelezo haya hayatajulikana na yatashughulikiwa kwa usiri. Unaweza kujiiondoa wakati wowote wakati wa mahojiano ikiwa hujisikii vizuri kujibu maswali. Mahojiano yatarekodiwa kwa uchambuzi zaidi baadaye na vidokezo pia vitachukuliwa wakati wa mahojiano. Rekodi zote na madokezo yaliyochukuliwa yatawekwa kwa usalama. (Thibitisha kwamba mshiriki anakubali kurekodi kabla ya kuendelea kama si kumaliza mahojiano). Mahojiano yatachukua kama dakika 30 hadi 45.

Kabla hatujaanza una swali lolote?

### **Sehemu ya A: Taarifaza Demografia ya mshiriki**

1. Una umri gani?

a) Miaka 18-40

b) Miaka 40-65

c) Miaka 65-75

d) Umri wa miaka 75 au zaidi

2. Sababu gani ya kutembelea hospitali leo?

- a) Ushauri
- b) Matibabu
- c) Ufuatiliaji
- d) Nyingine (tafadhali taja).....

3. Ulifanyiwa mastectomy lini?

- a) miezi 0-6
- b) miezi 6-12
- c) miezi 12-24
- d) > nondo 24

4. Unaishi wapi?

- a) Katika/ndani ya Nairobi
- b) Nje ya Nairobi

5. Hali yako ya ndoa ikoje?

- a. Ndoa
- b. Mtu mmoja
- c. Imetenganishwa
- d. Wameachwa
- e. Nyingine

6. Una watoto wangapi? .....

7. Kiwango chako cha elimu?

- a) Msingi
- b) Sekondari
- c) Elimu ya juu

d) Nyingine (taja).....

8. Dini yako ni ipi?

a) Mkristo

b) Muislamu

c) Mhindu

d) Nyingine (Bainisha).....

9. Kazi yako ni ipi? .....

10. Je, unalipia vipi matibabu yako na huduma zingine za saratani? (Anaweza kuchagua zaidi ya moja)

a) Bima ya afya ya taifa (NHIF)

b) Bima ya afya ya kibinafsi

c) Nje ya mfuko

d) Michango kutoka kwa familia na marafiki

e) Nyingine (taja).....

11. Ulijiandikisha lini katika kliniki ya huduma ya saratani katika KNH (taja mwaka na mwezi).....

12. Je, una matibabu gani kwa sasa au (ungependa) kuwa nayo hivi karibuni? (Inaweza kujaza zaidi ya moja ikiwa inatumika kwa washiriki)

a) Upasuaji

b) Tiba ya kemikali

c) Tiba ya mionzi

d) Tiba ya homoni

e) Tiba ya kinga mwilini

f) Tiba inayolengwa



## Maswali ya kuuliza:

Orodha hii ya maswali itamwongoza mtafiti. Si lazima ifuatwe kwa utaratibu au kikamilifu na majibu ya mshiriki yataongoza maswali pia.

## Sehemu ya B: Maswali navidokezo

Maswali	Vidokezo
Maswali ya awali	<ol style="list-style-type: none"><li>1. Je, ulijuaje kuhusu upasuaji wa matiti kama mfumo wa matibabu?</li><li>2. Je, ulikuwa na maoni gani ya awali kuhusu upasuaji wa matiti kama mfumo wa matibabu?</li><li>3. Je, ni lini na jinsi gani uliamua kutumia mfumo wa matibabu wa mastectomy?</li></ol>
Q1. Je, upasuaji wa matiti umekuathiri vipi wewe kimwili?	<ol style="list-style-type: none"><li>4. Je, taswira ya mwili wako imebadilika vipi kufuatia upasuaji wa matiti?</li><li>5. Je, upasuaji wa matiti umeathiri kivi: maisha yako ya kazi, maisha yako ya kawaida ya familia, Maisha yako ya ngono, utendaji wa kawaida wa kimwili</li><li>6. Je, unapata maumivu yoyote ya mwili kwa sababu ya kufanyiwa upasuaji wa matiti na ni kwa jinsi gani unakabiliana nayo?</li><li>7. Katika kiwango cha kibinafsi, unahisije kimwili kufuatia upasuaji wa matiti?</li></ol>
Q2. Je, upasuaji wa matiti umekuathiri vipi wewe kisaikolojia?	<ol style="list-style-type: none"><li>8. Je, upasuaji wa matiti umeathirije kujistahi kwako?</li><li>9. Je, umekumbana na hisia za mfidhaiko au wasiwasi kufuatia upasuaji na kama ni hivyo, unaweza kuzihusisha na nini?</li><li>10. Je, upasuaji wa matiti umekuathiri vipi kisaikolojia?</li></ol>
Q3. Je, upasuaji wa matiti umeathiri vipi maisha yako ya kijamii?	<ol style="list-style-type: none"><li>11. Eleza uhusiano wako na wanafamilia wengine tangu</li></ol>

	<p>kufanyiwa upasuaji wa uzazi?</p> <p>12. Je, upasuaji wa matiti umeathiri vipi uhusiano wako wa karibu/kimapenzi na mwenzio wa ndoa?</p> <p>13. Je, upasuaji wa matiti umeathiri vipi majukumu yako ya kijamii (katika viwango vya familia na jamii) (k.m kupoteza utambulisho, kutengana au talaka n.k)? Je, kumekuwa na mabadiliko? Ikiwa ndivyo, ni mabadiliko gani?</p>
<p>Q4. Je! ni aina gani za mifumo ya usaidizi iliyopo kwa wagonjwa walio na saratani ya matiti baada ya upasuaji wa matiti?</p> <p>a) Ushauri b) Ushirika wa kikundi c) Urekebisho ya matiti imepasuliwa</p>	<p>14. Je, ni aina gani ya usaidizi umepokea tangu kufanyiwa upasuaji wa matiti (ukiwa nyumbani na hospitalini)? Usaidizi huo umesaidia na ikiwa ni kwa njia zipi?</p> <p>15. Ni mapendekezo gani unaweza kutoa kuhusu usaidizi unaohitajika kwa wagonjwa wa saratani ya matiti ambao wamefanyiwa upasuaji wa mastectomy?</p>
<p>Q5. Je, kuna taarifa nyingine yoyote ambayo ungependa kuongeza kuhusu uzoefu na mitazamo wako kuhusu utunzaji wa wagonjwa wa saratani ya matiti?</p>	<p>Ikiwa kuna yoyote, tafadhali endelea ...</p> <p>Ikiwa hakuna basi ningependa kushukuru kwa ushiriki wako katika utafiti huu.</p>

### **Vifaa za mahojiano**

- a) Fomu za idhini (nakala moja kwa washiriki, nakala moja kwa timu)
- b) Mwongozo wa Mahojiano kwa Mwezeshaji
- c) Kifaa cha kurekodi
- d) Chaja ya kifaa cha kurekodi.

**Ahsante**

## Appendix 5: Approval Letter from KNH-UoN Ethics Committee



UNIVERSITY OF NAIROBI  
FACULTY OF HEALTH SCIENCES  
P O BOX 19678 Code 00202  
Telegrams: varsity  
Tel: (254-020) 2726300 Ext 44355



KENYATTA NATIONAL HOSPITAL  
P O BOX 20723 Code 00202  
Tel: 726300-9  
Fax: 725272  
Telegrams: MEDSUP, Nairobi

KNH-UoN ERC  
Email: [uonknh\\_erc@uonbi.ac.ke](mailto:uonknh_erc@uonbi.ac.ke)  
Website: <http://www.erc.uonbi.ac.ke>  
Facebook: <https://www.facebook.com/uonknh.erc>  
Twitter: @UONKNH\_ERC [https://twitter.com/UONKNH\\_ERC](https://twitter.com/UONKNH_ERC)

Ref: KNH-ERC/A/35

23<sup>rd</sup> January, 2023

Mary Akinyi Owino  
Reg. No. H56/37558/2020  
Dept. of Nursing Sciences  
Faculty of Health Sciences  
University of Nairobi



Dear Mary,

**RESEARCH PROPOSAL: EXPLORING EXPERIENCES OF INDIVIDUALS WITH BREAST CANCER POST-MASTECTOMY AT KENYATTA NATIONAL HOSPITAL; A PHENOMENOLOGICAL QUALITATIVE STUDY (P588/07/2022)**

This is to inform you that KNH-UoN ERC has reviewed and approved your above research proposal. Your application approval number is P588/07/2022. The approval period is 23<sup>rd</sup> January 2023 – 22<sup>nd</sup> January 2024.

This approval is subject to compliance with the following requirements;

- i. Only approved documents including (informed consents, study instruments, MTA) will be used.
- ii. All changes including (amendments, deviations, and violations) are submitted for review and approval by KNH-UoN ERC.
- iii. Death and life threatening problems and serious adverse events or unexpected adverse events whether related or unrelated to the study must be reported to KNH-UoN ERC 72 hours of notification.
- iv. Any changes, anticipated or otherwise that may increase the risks or affected safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH-UoN ERC within 72 hours.
- v. Clearance for export of biological specimens must be obtained from relevant institutions.
- vi. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. Attach a comprehensive progress report to support the renewal.
- vii. Submission of an executive summary report within 90 days upon completion of the study to KNH-UoN ERC.

Protect to discover

Prior to commencing your study, you will be expected to obtain a research license from National Commission for Science, Technology and Innovation (NACOSTI) <https://research-portal.nacosti.go.ke> and also obtain other clearances needed.

Yours sincerely,




**DR. BEATRICE K.M. AMUGUNE**  
**SECRETARY, KNH-UoN ERC**

- c.c. The Dean, Faculty of Health Sciences, UoN  
The Senior Director, CS, KNH  
The Assistant Director, Health Information Dept., KNH  
The Chairperson, KNH- UoN ERC  
The Chair, Dept. of Nursing Sciences, UoN  
Supervisors: Dr. Miriam C.A. Wagoro, Dept. of Nursing Sciences, UoN  
Dr. James Mwaura, Dept. of Nursing Sciences, UoN

**Appendix 6: Approval Letter from Kenyatta National Hospital**

KNH/R&P/FORM/01



**KENYATTA NATIONAL HOSPITAL**  
P.O. Box 20723-00202 Nairobi

Tel.: 2726300/2726450/2726565  
Research & Programs: Ext. 44705  
Fax: 2725272  
Email: knhresearch@gmail.com

### Study Registration Certificate

- Name of the Principal Investigator/Researcher  
MARY AKINYI DWINDO
- Email address: MaryDwindo1979@gmail.com Tel No. 0722964061
- Contact person (if different from PI).....
- Email address:..... Tel No.....
- Study Title  
EXPLORING EXPERIENCES OF INDIVIDUALS WITH BREAST CANCER POST MASTECTOMY AT KENYATTA NATIONAL HOSPITAL: A PHENOMENOLOGICAL QUALITATIVE STUDY
- Department where the study will be conducted CANCER TREATMENT CENTRE (CTC)  
*(Please attach copy of Abstract)*
- Endorsed by Research Coordinator of Department where study will be conducted.  
Name: ROSELYNE OKUMU Signature [Signature] Date 27/1/2023
- Endorsed by KNH Head of Department where study will be conducted.  
Name: [Signature] Signature [Signature] Date 27/1/23
- KNH UoN Ethics Research Committee approved study number P588/07/2022  
*(Please attach copy of ERC approval)*
- I MARY AKINYI DWINDO commit to submit a report of my study findings to the Department where the study will be conducted and to the Department of Medical Research.  
Signature [Signature] Date 27/01/2023
- Study Registration number (Dept/Number/Year) \_\_\_\_\_ / \_\_\_\_ / \_\_\_\_  
*(To be completed by Medical Research Department)*
- Research and Program Stamp \_\_\_\_\_

All studies conducted at Kenyatta National Hospital must be registered with the Department of Medical Research and investigators must commit to share results with the hospital.

## Appendix 7: Work plan

	2022		2023						
Activity / Weeks	Aug – Dec		Jan	Feb	Mar	Apr	May	Jun	Jul
Research Proposal development and supervisor clearance	■								
Submission to KNH-UoN ERC and approval			■						
Questionnaire pretesting				■					
Data collection and cleaning					■				
Data processing and Analysis						■			
Report Writing						■			
Draft report presentation and corrections to the supervisor							■		
Final report presentation and Submission to the supervisor								■	
Department Research finding a defense									■



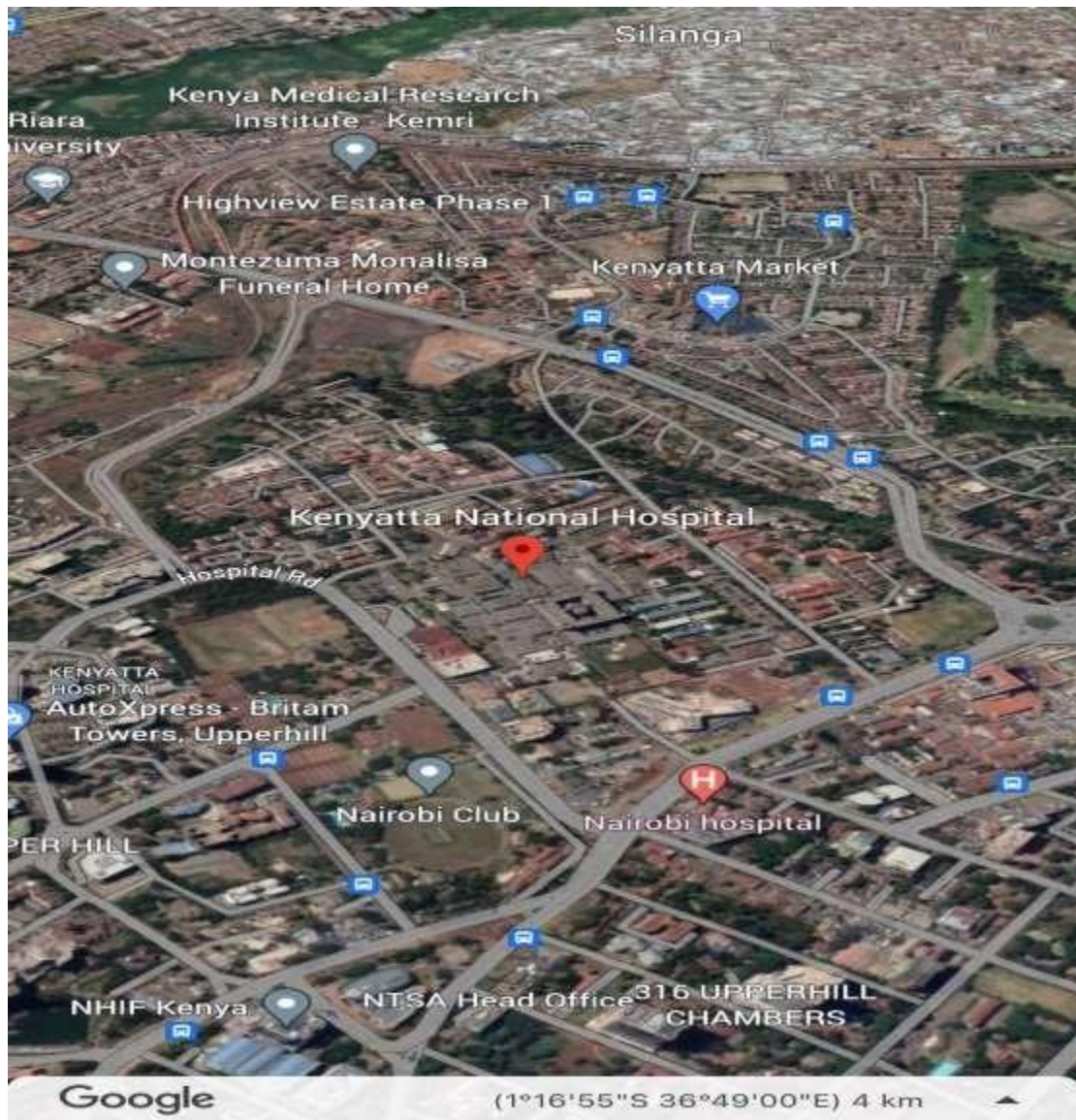
## Appendix 8: Budget

Budget Component	Description	Item	Unit Of Measurement	Unit of cost (Kshs)	Total cost (Kshs)
Literature review	Personal literature search, transport and use of Wi-Fi	Browse for literature in journals, dissertations, books	10 weeks	@1000	15,000
Stationary	A ream of A4 papers	1	@800	800	800
Digital voice recorder		1		5000	5000
Proposal Development	Typing and printing	Proposal typing	3 drafts, 60 pages each	@500	1,500
Proposal printing	3 drafts, 60 pages each	3	@500	1500	1500
Photocopy charges	6 drafts, 60 pages each	@400	2,400	2400	2400
Ethical Approval	KNH/UON Ethics	1	@2000	2,000	2000
Data Collection and Analysis	Pretesting	Printing and photocopy	5 copies	@50	250
		Transport and subsistence	1 day	@1000	1,000
FGD guidelines and consent forms	Photocopy	35 copies	@50	1,750	1750
Data collection	Lunch	20 days	@500	10,000	10000

	Transport and subsistence	4 Weeks (20days)	@1000	20000	20000
Data analysis	Statistician	@60,000	60,000		60,000
Subtotal					101,200
Report	Draft report	Typing, printing and photocopy	150 pages, 5 copies	@30 @600	4,500 3,000
Final report	Correction and printing	150 pages	@10	1,500	Final report
Final report	Correction and printing	150 pages	@10	1,500	1500
Photocopying	5 copies	@600	3,000		3000
Binding	7 copies	@1000	7,000		7000
Dissemination	Dissemination report	Typing and printing	20 pages	@30	600
Photocopying	50 copies x 20	@5	5,000		5000
Binding	10 copies	@50	500		500
Researcher's Fee	Principal Researcher	@50,000	50,000		50,000
Contingencies (10%)	8,630				12630
Subtotal					89230
Total					220,430



## Appendix 9: Study site map



## Appendix 10: plagiarism report

### Exploring Experiences of Individuals with Breast Cancer Post-Mastectomy at Kenyatta National Hospital: A Phenomenological Study

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*Atieno MCW*  
13th November, 2023

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