# LYMPHEDEMA MANAGEMENT OUTCOMES AND THEIR DETERMINANTS AMONG PATIENTS TREATED FOR BREAST CANCER AT SELECTED HOSPITALS IN WESTERN REGION OF KENYA

**Rosemary Lusike Wepukhulu**

**A Thesis Submitted in Partial Fulfillment of the Requirements for the Award of the Degree of Masters of Science in Advanced Nursing Practice (Oncology - Palliative Nursing) of Masinde Muliro University of Science and Technology**

**November, 2023**

## DECLARATION

This thesis is my original work prepared with no other than the indicated sources and support and has not been presented elsewhere for a degree or any other award.

Signature…… Date……

Rosemary Wepukhulu

HNR/G/07/2016

## CERTIFICATION

The undersigned certify that they have read and hereby recommended for the acceptance of Masinde Muliro thesis 'entitled '**Lymphedema Management Outcomes and their Determinants among Patients Treated for Breast Cancer at Selected Hospitals in Western Region of Kenya.'**

Signature…… Date……

**Prof. Lt. Col. (Rtd) John M. Okoth**

Department of Nursing Research, Education and Management,

Masinde Muliro University of Science and Technology

Signature…… Date……

**Dr. Damaris A. Ochanda**

Department of Nursing Research, Education and Management,

Masinde Muliro University of Science and Technology

## DEDICATION

To Breast Cancer Survivors with Love.

## ACKNOWLEDGEMENTS

I thank God and express my appreciation to all those whose persistent efforts made seemingly impossible tasks possible during my study. First and foremost, I would like to express my gratitude to Masinde Muliro University of Science and Technology for giving me an opportunity to pursue my studies and the directorate of post graduate studies (DPS) for approving my research thesis. This study, just like many research assignments, require the wisdom, assistance and support from many people who either directly or indirectly made contributions to its planning, processing, execution and outcome. It may not be possible to mention all of them but sincerely thank all of them. I extend my appreciation to IREC MMUST. IREC Kisumu and to the directors of education and health and medical superintendents of specific hospitals in the following- counties Kakamega, Bungoma, Kisumu, Siaya and Bomet for clearance to carry out the study in their respective counties. Am thankful to Prof. John Okoth and Dr Damaris Ochanda for mentorship and positive criticism suggestions, during consultations. Finally, my special thanks to my Husband Jackton for his moral and financial support. My daughters Verlianie and Tracy, and Sons Carl and Ian for their constant encouragement.

## ABSTRACT

Globally, 28% to 38% of breast cancer survivors develop lymphedema following breast treatment affecting one in five patients, Symptoms vary but include swelling, heaviness and pain, when severe, significantly impact the person's ability to perform tasks. Without treatment the condition progresses to serious complications such as necrosis and infection. In Sub-Saharan Africa reported comorbidities associated with lymphedema showed it is on the increase. Kenya has no data on the prevalence of lymphedema, although reports exist on different types of lymphedema treatment. In western Kenya, no studies have examined lymphedema related to breast. This study evaluated clinical management strategies for lymphedema secondary to breast cancer treatment in selected hospitals in western region of Kenya. Specific objectives were to assess healthcare providers competence in clinical management of lymphedema secondary to breast cancer treatment, to examine the effectiveness of strategies used in clinical management of lymphedema and determine lymphedema patient management outcome. Study design was cross sectional analytic. included were health care providers and patients in the selected oncology centers. A pretest was carried out at Vihiga county referral hospital. Data collection was by a self-administered questionnaire, observation check list and focus group discussion. Qualitative data was analyzed thematically. Quantitative data was analyzed using descriptive statistics, frequencies and percentages and inferential statistics were used to test the association of variables. The results showed knowledge ranging from with deficit in important areas of practice such as skin care (OR = 0.56, p = 0.01). Stocking class, A pressure (OR = 1.841, p = 0.004). With over 50% getting incorrect answers**.** Better skills demonstrated in history taking and assessment (OR;1.6:CI:1.0-2.4; p value =0.037). Bivariate analysis showed statistically significant results of patients developing lymphedema after single agent surgery (OR;0.1 CI 0.0-0.8 P Value =0.004) or combined treatment Chemotherapy and Hormonal therapy, (OR:0.5;CI;0.1-0.8,P Value =0.003). Borderline statistically significant results were also obtained from those on the combination of Surgery, Chemotherapy, Radiotherapy and Hormonal therapy OR;0.5; CI: 0.1-0.4 P Value = 0.065. The asymmetrical distributions showed some patients took several months to development lymphedema symptoms and used more than one treatment strategies, the highest proportion used prescribed exercise (58.8%) and medical treatment (59.4%) and Management strategies varied with a significant difference in response to each treatment and not all treatment strategies were effective. there was statistically significant difference in outcome to treatment strategies. When using medical treatment as patients were likely to report improvement (OR:3.3; 95%CI: 1.6-6.5: P =0.005, physical exercises (OR:1.6; 95% CI: 1.1-3.2: P =0.032), In conclusion, healthcare providers were not knowledgeable and strategies were effective when the diagnosis was made early. The study recommended training opportunities and continuing education for healthcare providers.

## TABLE OF CONTENTS

## LIST OF TABLES

**TABLE** **PAGE**

## LIST OF FIGURES

**FIGURE** **PAGE**

## LIST OF APPENDICES

**APPENDIX** **PAGE**

## LIST OF PLATES

**PLATE** **PAGE**

## LIST OF ABBREVIATIONS AND ACRONYMS

| | |
|---|---|
| **AMRS** | Academic Model Medical Records System |
| **BCRL** | Breast Cancer Related Lymphedema |
| **BLS** | British lymphedema society |
| **BMI** | Body Mass Index |
| **CB** | Compression bandaging |
| **CDT** | Complex Decongestive Therapy or Complete Decongestive Therapy |
| **CPSI** | Canadian patient safety institute |
| **ISL** | International society of lymphedema improvement |
| **LD** | Lymphatic drainage |
| **MLD** | Manual Lymphatic Drainage |
| **MT** | Medical treatment |
| **NLN** | National Lymphedema Network |
| **No imp** | No improvement |
| **PE** | Physical exercise |
| **Rx** | Treatment |
| **SLE** | Secondary Lymphedema |
| **SM** | Self-massage |
| **SUR** | Surgery |
| **TSPMR** | Turkish society of physical medicine and rehabilitation |

## OPERATIONALIZATION OF KEY TERMS

**Clinical management :**This refers to the prosses of understanding of and providing care to lymphedema patients in a hospital setting to achieve an optimal level of wellness while providing none duplicative services.

**Clinical management strategies :**This is an aspect of lymphedema patient care that include agreed upon principles and practices in a hospital setting that include history taking, physical examination, investigations diagnosis, structured and ongoing assessments, prevention of severity of symptoms, treatment and evaluation by knowledgeable health care providers .

**Compression Bandages/Garments :**A gauze sleeve, soft cotton wraps or a high-density foam of 2-3 layers of short stretch bandages designed to apply pressure to the affected limb to drain fluid and stop further accumulation.

**Deep Skin Fold :**Is a sign of severe lymphedema where the skin becomes thick with folds and bulges that cannot be easily pinched.

**Effective clinical management:** This is achieving desirable control of lymphedema symptoms by evaluating the care, in this study care was evaluated by asking patient the symptoms they suffered and how the treatment provided helped them in improving the symptoms.

**Extensional debulking :** Removing as much fat as possible to reduce the overall size of the limb to relieve symptoms .

**Healthcare providers :**These are clinicians taking care of lymphedema patients, who are Doctors, Nurses, clinical officers, physiotherapists and Nutritionists

**Liposuction** :This is a surgical procedure done to patients with fatty changes in the skin by the surgeon to remove excess and reduce the size of the limb

**Lymphedema Assessment:** Evaluation of lymphedema symptoms at different intervals by taking patients' history, physical examination, vital signs and limb measurements.

**Lymphedema secondary to breast cancer treatment :**This is arms or shoulder edema in breast cancer patients caused by the interruption of the flow of axillar lymphatic system as a result of breast cancer treatment such as surgery, radiotherapy or chemotherapy that causes injury and healing by scaring which results in the accumulation of the lymph fluid in the subcutaneous tissues

**Manual lymph drainage :**Light massage techniques applied by healthcare providers to encourage removal of excess interstitial fluid and increase lymphatic transport towards the right direction where it can be drained.

**Stemmer's sign :** It is a physical examination finding used to diagnose or evaluate lymphedema if the healthcare care provider cannot pinch the dorsum of the limb skin then it is positive .

# CHAPTER ONE

# INTRODUCTION

## 1.1 Overview

This chapter represents the study background, problem statement, objectives, research questions, justification, limitations and the conceptual framework.

## 1.2 Background of the Study

Globally breast cancer remains the most diagnosed cancer with approximately 2.3 million cases in both sexes. In sub-Saharan Africa breast cancer is reported 12.7% of the total cancers with central, western and eastern Africa reporting lower incidence rate compared to southern Africa that is 33.4 per100,000 cases. . Survival rate considerably lower in this region with estimates of two women diagnosed with the disease dying within five years of diagnosis **(**Kantelhard, *et al.,* 2018).

Treatments for breast cancer such as surgery, radiation, chemotherapy, and hormonal therapy chemotherapy are focused on improving symptoms but unfortunately, damages the bone marrow and makes it less able to produce blood cells leading to vulnerability to infection, the prosses which causes scarring and stasis of lymphatic fluid causing build up in the interstitial tissues (Armer *et al.,* 2016). Decreased lymphatic drainage and accumulation of lymph fluid in the skin and subcutaneous tissues causes lymphedema a health challenge and long term most occurrence after treatment (Wanchaiet al, 2016).

About, 28% to 38% develop lymphedema following breast cancer treatment affecting one in five patients, without treatment the condition progresses to serious complications and significantly impact the person's ability to perform tasks (Sung *et al.*,2020).Lymphedema is a chronic and incurable condition that is characterized by

impaired drainage of lymphatic fluid that increases stasis in the skin and subcutaneous tissues (Krok-Schoen *et al.,* 2015). Breast cancer- related lymphedema is precipitated by an interruption of the lymphatic vessels either from physical distraction, compression of the lymphatic channels, tumor inversion and injury during surgery that remove or damage the lymph nodes, chemotherapy, or radiation therapy (Heisig *et al.,* 2016). Lymphedema is clinically defined as swelling of at least 200mls by volume or 2cms by circumference measurement of the affected limb that may develop anytime from initial treatment to the period of 20 years (Shaitelman *et al.,* 2015).

According to systemic research carried out in south Africa between February to June 2017, genetic variations such as a single-nucleic polymorphing (SNPs) involved in inflammation pathway can modify a patient's physiological reaction to trauma and cause secondary lymphedema (Milambo *et al.,* 2018). Obesity of the BMI more than 30 during and after treatment has been identified as an important acquired risk factor where lymphatic channel are compressed by large fatty deposits to cause either mechanical destruction or complete obstruction and increase the risk for lymphedema (Keast & Towers, 2017).

Patient report symptoms of discomfort and heaviness full sensation of arm, skin filling tight decreased flexibility and swelling in specific areas that manifested in early stages (Stewart *et al.,* 2015). Skin thickening and hardening, joint immobility, pain and, pitting of tissues, skin folds and massive swelling and leakage of lymph are noted in later stages (Armer *et al.,* 2016). And early detection and intervention is key in risk reduction and management of this wide spread condition (Milambo *et al.,* 2018).

In the United States 28% to 30% developed Lymphedema the five-year incidence ranging from 43%-94%. It is a wide spread problem affecting one in five patients (Gillespie *et al.,* 2017). It affects the individual's lifestyle and causes physical and psychological problem and negatively affecting the persons way of living (Armer *et al.,* 2016).

In Sub Saharan Africa, a baseline incidence of lymphedema of 11.7-17.3 % was reported in breast cancer patients who presented with advanced disease that increase the risk of lymphedema(Ayre &Perker.(2019). In Nigeria as in many parts of sub-Saharan Africa the subject of lymphedema has been under estimated with very limited data on its prevalence and management(Marchica *et al.,*2021). according to Mathers *et al.,* (2015) the reported comorbidities show that it is on the increase, in low- and middle-income countries.

In Kenya according to Riogi (2015) in Aga Khan University Hospital, lymphedema swelling develops slowly over a time and ranges from months to many years Once the patient develops lymphedema, is unable to carry out self-care nor provide for significant others. Surgery include bypass and limb reduction procedures can cure 30-40% of the cases, while conservation therapy leads to an improvement of symptoms (Sawers *et al.,* 2020). Knowledge of lymphedema regarding symptoms, diagnosis and risk reduction and different treatment options by healthcare providers allow them to offer good quality care (Runowicz *et al.,* 2016). Health care providers need greater awareness of physical and psychological effects of lymphedema through good history taking, physical examination and any subsequent investigations are important to reveal the extent of the problem. Integration of other skills such as limb volume measurements, skin care, care of the compression garments, lymphatic drainage and a

multidisciplinary approach strengthen the resources leading to improvement of symptoms and prevention of complications (Borman *et al.,* 2018).

### 1.3 Statement of the Problem

Lymphedema affects 140 to 250 million people worldwide (Foldi *et al.,* 2021). The overall estimated incidence in a recent meta-analysis was 21.4% show that breast cancer related lymphedema is a wide spread problem affecting one in five patients after treatment (Gillespie *et al.,* 2017).

Lymphedema is considered one of the most distressing complications and an important sequela of breast cancer treatment, associated with the feeling of discomfort, and heaviness. Early detection and intervention are key in risk reduction and management of this wide spread condition in breast cancer patients who have undergone treatment (Milambo *et al.,* 2018).

In African countries although, there is scarce data on the prevalence, and management of breast cancer related lymphedema reported comorbidities associated with this condition, show that it is on the increase (Mathers *et al.,* 2015).

In Ghana, Sekyere, (2018) reported 9.9% of the patients treated for breast cancer developed lymphedema. Reviews in the Democratic Republic of Congo (DRC) by Jacgues *et al.,* 2018). revealed advanced cure of lymphedema in the developed countries with limited data on BCRL risk factors in this country and the authors recommended that studies to be conducted to extend the body of knowledge, skills, and awareness of secondary lymphedema (Milambo *et al.,* 2018).

In Kenya, although there is no data indicating the prevalence of lymphedema, Wamalwa *et al,* (2019) reported that between 2014 to 2017 twenty patients underwent lymph node transplant in both public and private hospitals to improve symptoms of stage two lymphedema for patients who did not respond to none surgical interventions.

In Western Region of Kenya, no study examined clinical management strategies for lymphedema related to breast cancer but research conducted at the Moi teaching and referral hospital on Kaposi's sarcoma in HIV patients provided insight in how lymphedema can lead to physical and psychological symptoms and progressive functional impairment (Park *et al.,* 2018).

In Kakamega County Referral Hospital between January to December 2018 of the 121 cases seen in oncology clinic with breast cancer 20% developed lymphedema which is not studied. Although lymphedema is a common complication, patients and care providers ignore the painless stage (Kayiran *et al.,* 2017). Once underdiagnosed, lymphedema leads to devastating consequences on the patients and their family members (Torre *et al.,* 2015).

To control lymphedema symptoms health care providers, require understanding the extent of the problem of lymphedema for accurate assessment, diagnosis and management (Ayre & Parker, 2019). It is therefore important that the diagnosis is made by competent healthcare providers who have knowledge on assessment and diagnosis, to determine appropriate treatment for each patient with lymphedema. A better understanding of the disease, Skill integration and utilization of management strategies allow the healthcare team to offer more comprehensive care to patients (British Lymphology Society, 2016). Since data of knowledge in developing countries is limited (Jacques *et al.,*2018). The findings of this study shall build knowledge of

lymphedema and improve patient care. This study therefore seeks to evaluate lymphedema management outcomes and their determinants among patients treated for breast cancer at selected hospitals in western region Kenya.

### 1.4 Main Objective

Evaluate lymphedema management outcomes and their determinants among patients treated for breast cancer at selected hospitals in western region of Kenya

### 1.5 Specific Objectives

1. To assess the competence of healthcare providers in clinical management for lymphedema secondary to breast cancer treatment.
2. To examine effectiveness of strategies used in the management of lymphedema secondary to breast cancer treatment.
3. To determine the outcome of lymphedema patients' management.

### 1.6 Research Questions

1. How competent are healthcare providers in clinical management strategies for lymphedema secondary to breast cancer treatment?
2. How effective are clinical management strategies for lymphedema secondary to breast cancer treatment ?
3. How is lymphedema patients treatment outcome in selected hospitals?

### 1.7 Justification of the Study

Breast cancer and its treatments lead to lymphedema a lifelong, distressing complication associated with the feeling of discomfort(American cancer society, 2016).The findings shall build knowledge of lymphedema for improving the care of patients. Generate other studies that will help improve symptoms of people with

lymphedema. Help in informing policies regarding lymphedema care and finally, the knowledge explored from this study shall be an input in cancer centers for future research.

### 1.8 Limitations of the study

Based on cross-sectional research design, data was collected at one point in time and therefore this study could not be generalized to a larger population. Since the aim of this study was to focus on lymphedema, other articles reporting on knowledge of health care providers on cancer survivors were excluded and there has been extensive research in such fields in the literature while lymphedema has not been addressed properly.

### 1.9 Conceptual Framework of the study

The conceptual frame work in this study was based on Donabedian model, with modification to suit the objectives. a conceptual framework that examines health services and evaluation of care, a model of Bravana *et al.*,(2017). To control lymphedema, Healthcare providers require knowledge and integration of skills in assessing, diagnosing, and treatment modalities. Patients factors are important because they influence the outcome.

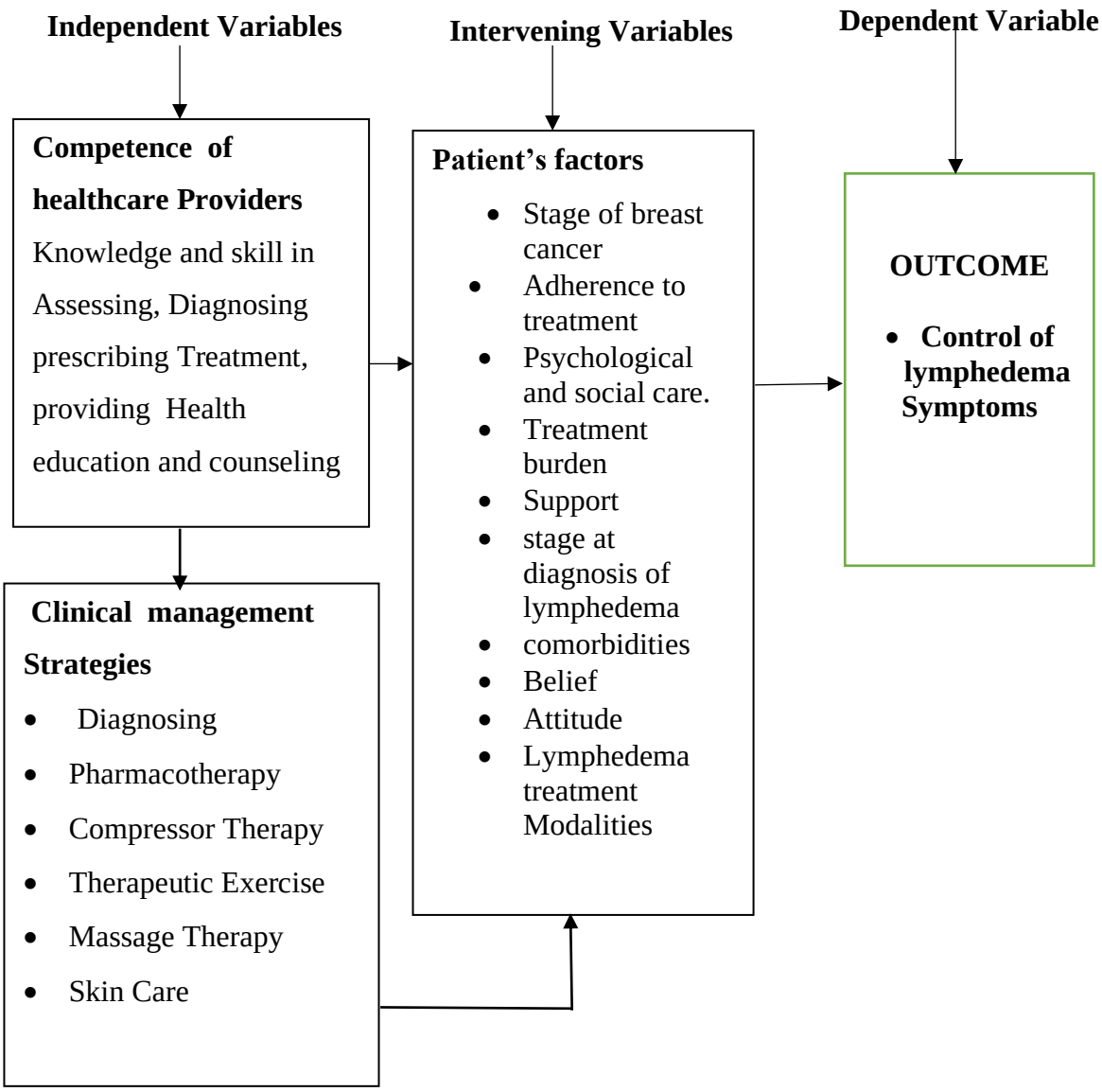


**Figure 1.1 Conceptual Frame work**
source : Bravana *et al.*,(2007)

# CHAPTER TWO

# LITERATURE REVIEW

## 2.0 Overview

This chapter presents the literature related to the concepts of lymphedema in breast cancer, describes the healthcare providers competence in effective clinical management of lymphedema, strategies, and patients' factors, treatment outcome, effective management and the research gap.

## 2.1 Introduction

Lymphedema is a lifelong side effect following breast cancer treatments that has devastating consequences on the quality of life of people treated for breast cancer (American Cancer Society, 2016). Three to five million people in the United States suffer from lymphedema after breast cancer treatments. The incidence after mastectomy ranges from 6% to 48% depending on the type of surgery (Ridner *et al.,* 2012). It is precipitated by an interruption of the flow of the axilla lymphatic system following breast cancer treatment due to physical distraction, compression of the lymphatic channels, tumor inversion, injury during surgery, chemotherapy, or radiation therapy as a result either blocking or narrowing the lymph channels (Heisig *et al.,* 2016).

Breast cancer related lymphedema (BCRL) is a potential complication following treatment that is characterized by massive swelling of the limbs (Torre *et al.,* 2015). It occurs after the damage to the lymphatic system and lymph fluid is channeled to the interstitial tissue and forming edema (Armer *et al,* 2016). It is clinically defined as swelling of at least 200mls by volume or 2cms by circumference measurement of the affected limb, some studies have shown that the onset of lymphedema symptoms can occur at any time post breast cancer treatment. 33% develop lymphedema 6 months to

8 months after treatment (Hayes *et al.*,2016) to 30 years post treatment (Armer *et al.*, 2017).

Armer *et al.*, (2015) described lymphedema as a set of pathological conditions due to dysfunctional lymphatic channels in which causes a buildup of protein rich fluid to accumulates in the skin and tissues that occurs when the lymph vessels or nodes in which fluid travels are either missing, removed or damaged. Several treatment factors have been associated with lymphedema such as axillary node involvement, the type of node surgery and radiation therapy which may compromise lymph node function and causing a degree of lymphedema (Mehrara *et al.*, 2019).

There is no cure for lymphedema therefore prevention should be emphasized by healthcare providers through health education, early diagnosis and early interventions to prevent severity of symptoms (James, 2012). Obesity, severe fatigue, susceptibility to infection and trauma to the lymphatic system such as surgery and radiation can increase the risk of developing lymphedema (Singer, 2009).

A study by Park *et al.*, (2018) reported 24.9% lymphedema that out of 450 women with breast cancer, the higher the staging the higher the extent of the disease. Axillary surgery and body mass index increased the risk of lymphedema while those who exercised regularly, received pretreatment education, and performed self-care activities decreased the risk for lymphedema. Lymphedema is diagnosed by a detailed medical history, which includes time of onset, location, cause of progression of pain and both objective and subjective assessment to determine the plan of care (Armer *et al.*, 2019).

### 2.1.1 The Onset and Progression of Lymphedema

Lymphedema develops in weeks, months, or years when the lymphatic system is damaged and the capacity to absorb excess water and cells from the interstitial space is reduced due to increased flow or decreased outflow (Michelini *et al.,* 2018). When lymphedema develop, the associated symptoms have an effect on the functional wellbeing and quality of life impaired. and plan of care is tailored to the individual presentation of disease (Heisig *et al.,* 2016). Appropriate management for lymphedema includes surgery and conservative management with medical and physical therapy (Sawers *et al.,* 2020).

### 2.1.2 Risks and Causes of Lymphedema

The superficial lymphatic vessels in the subcutaneous tissues provide drainage for the skin and the subcutaneous tissues and deep vessels provide drainage from the muscles, tendon sheaths, nervous tissues, periosteal and most joint assumed to function independently (Armer *et al.,* 2019). Lymphedema is caused by fluid in the skin or tissue areas that drain in the axilla these include lateral breast, chest, lateral and posterior upper trunk, arm, and hand. the interruption of the axilla lymphatic system is related to the extent of axillary node involvement, type of surgery, and radiation therapy. These factors lead to accumulation of fluid (Shaitelman *et al.,* 2015).

Surgery to the lymph vessels increases the chance for fluid not to drain properly and lead to the development of breast cancer related lymphedema (Armer *et al.,* 2016). Chemotherapy also destroys health tissues leaving them unable to drain fluid and weight gain as a result of hormonal changes, such as temporary or permanent menopause (cessation of menstrual periods) and/or fatigue that makes it hard to stay active and increase the risk of patients to lymphedema by reducing the flow of fluid (Rebegea *et al,* 2015).

When obese the demand for oxygen is increased which leads stasis of fluid and lymphedema result (Cheville *et al.,* 2003). Lymphedema may also occur from non-cancer conditions. Data shows that postoperative infection, higher body mass index and higher levels of hand use, chronic venous ulcerations or inflammation and late stages of breast cancer are risk factors for development and severity of lymphedema (Safwat *et al.,* 2017).

The incidence of lymphedema after mastectomy is higher compared to lumpectomy (Foldi *et al.,* 2021). Lymphedema manifestation is secondary to lymph fluid flow and stasis (Ayre & Parker, 2019). Inflammatory response to the chronic accumulation of protein containing fluid and adipose tissues increases the severity (Armer *et al.,* 2016). lymphedema is prevented from worsening when diagnosed and treated early. Strategies for management of lymphedema include, exercise, compression, and lymphatic massage that are effective in reducing the amount of swelling in affected limbs (Armer *et al.,* 2019).

### 2.1.3 Classification of Lymphedema

Lymphedema can be classified as primary or idiopathic and secondary or acquired, according to the age edema first appears, congenital (present at birth) lymphedema praecox (onset at time of puberty or at the third decade) and lymphedema tard appears after the age of 35 years. May result from the anatomical abnormalities of the lymphatic system (Milroy's disease). The lymphatic vessels may also be dilated and ecstatic (Mega lymphatic). And the lymphatic system may be obstructed (Ayre & Parker, 2019).

Secondary lymphedema is due to an extrinsic interruption of the lymphatic drainage, result from trauma, surgery to the axilla. radiation therapy chemotherapy, scarring and metastasis to the lymph nodes that block the lymph flow and cause proximal collection of fluid. These factors decrease lymphatic drainage and increase stasis of fluid in areas of the skin and subcutaneous tissues (Ayre & Parker, 2019).

### 2.1.4 Signs and Symptoms of Lymphedema

Suehiro *et al.,* (2014) states that Lymphedema symptoms leads to impaired function and immobility and interruption of daily activities. In a cross-sectional study by Armer *et al.,* (2015) showed 64 patients with BCRL reported a symptom cluster that included alteration in limb sensation, loss of confidence in body, decreased physical activity, fatigue and physical distress. In a cross-sectional descriptive study (Armer & Whitman, 2002) reported symptoms most experienced by lymphedema patients were swelling (63%) heaviness (60%) tenderness (45%) and numbness (38%). Lymphedema may also have severe consequences on self-care and failure to provide care to the entire family. The weight and the size of the limb may affect self-esteem resulting in the feeling of hopelessness and dependence and self-isolation (Connell *et al.,* 2013)

**Plate 2.1 lymphedema of the left arm**

### 2.2 Healthcare providers' competence in management of lymphedema

To understand the nature of lymphedema and its treatments, Healthcare providers should be competent in diagnosis, early detection, health promotion and complexed interventions (Armer *et al.*, 2021). And must approach this complexed with fundamental knowledge and skills to provide the best patient outcome (Kayiran *et al.*, 2017).

#### 2.2.1 Healthcare Providers' Knowledge on clinical Management of Lymphedema

Mergan *et al.*, (2016) reported that limited knowledge regarding lymphedema by healthcare providers and access to health services by patients lymphedema management challenging. Healthcare providers require knowledge of the potential risks' factors for lymphedema, and perform overall assessment for early detection during practice (Ayre & Parke, 2019).

Healthcare providers use their knowledge to provide care and support patients in their self-care responsibility (McCaulley & Smith, 2014).when making practice and policy decision, health care providers, use clinical expertise, clinical context and recourses to make decisions and support patients in their self-care responsibilities reduce the risk factors and prevent lymphedema that leads to positive patients' outcome (Ayre & Parker, 2019). Healthcare providers should work as a team and organization commitment is a key aspect required to provide appropriate patient care by address challenges in treating and managing lymphedema (Papadopoulou *et al.,* 2012).

In the United Kingdom the study on self-reported competence by health care providers, survivorship services provision after breast cancer treatment stated that specialty nurses are important for the quality service provided (Corner *et al.,* 2013). American Nurses' Association (ANA) stated the nurse are team leaders and play an important role in helping patients take responsibility of their own condition (Chubak *et al*, 2014).

In the official published Gazette dated April 19$^{th}$ 2011 of the Amendment of nursing regulations, nurses have the responsibilities of symptom management and provision of support to improve the quality of life for patients and their families. In a study done in Iran in 2015, several sub competences were identified under holistic physical care, psychological and social care. Ability to prevent three levels of disease and inter professional competences such as management and leadership competencies with the nurse practitioners as team leaders (Michelini *et al.,* 2018).

Lymphedema treatment is a complicated therapeutic regimen and is the less likely patients are able to adhere to therefore, in order to provide care for patients across the multiple care agencies to implement this package it is important that well trained and

competent care providers consider the burden of the treatment and the ability of the patient to overcome treatment barriers (Ayre & Parker, 2019).

In summary, understanding all aspects of care and patients treatment outcome have identified the need for healthcare providers to become knowledgeable about lymphedema giving the best opportunity for more efficacious treatment and subsequent preservation of quality of life (Shaitelman *et al.,* 2015).

### 2.2.2 Healthcare provider's skills on clinical management of lymphedema

Healthcare providers play a critical role in lymphedema management, but must approach the complexity with foundational knowledge and skills to provide the best outcome (Kayiran *et al.,* 2017). Lymphedema should be diagnosed by qualified health providers with appropriate training so it's their responsibility that they have the knowledge, skills and each other's support to meet the defined needs of each patient (Borman *et al.,* 2018).

Healthcare providers depend on practical efficiencies and tests in order to accurately, assess diagnose and manage lymphedema and also monitor progression and regression of the disease. Healthcare providers require skills in history taking, physical examination, Assessment by inspection, palpation and percussion and diagnosis, to reveal the nature and extend of the problem (British Lymphology Society 2016). Integration of other skills such as limb volume measurements, skin care, bandaging, gentle rhythmic massage, care of the compression garments and health education and counselling and multidisciplinary approach prevent the development of complications (Jacobs *et al.,* 2020).

## 2.3 Strategies used in clinical management of lymphedema

### 2.3.1 Introduction

The diagnosis can be made following a comprehensive initial assessment by clinicians and determine appropriate treatment for each patient with lymphedema. The diagnosis confirmed by venous doppler studies, magnetic resonance imaging or computed tomography scans (Armer *et al.,* 2016). History of previous medication, onset and extent of symptoms, physical examination to rule out any abnormalities and volume of the affected limb to assess deviation from normal (Shigaki *et al.,* 2013). Patient's care should be structured and ongoing as the disease progresses to prevent severe consequences on the patients (Kayiran *et al.,* 2017).

Todd (2015) states that lymphedema needs a multi-disciplinary approach in a tailored program for positive effect of care. Nurses uses empathy and practice professionalism by allocating sufficient time to meet and consult with patients and their families and commitment to honest and integrity ethics. Educate and counsel the patients by applying the principles of education using appropriate teaching methods, apply the principle of critical thinking and develop appropriate solutions to identified problems and work together in all aspects of management focused on the improvement of quality of life (Fialka-Moser *et al.,* 2013).

### 2.3.2 Assessment and Diagnosis

History of presenting illness determines the onset of the symptoms, and triggering events and attempted treatments, surgical history and current medication is key in treatment plan (Stewart & Shamdasani 2014). Subjective report of sensation, heaviness, tightness and pulling changes may be helpful in diagnosis of breast cancer related lymphedema and may be the indicator of interstitial pressure or measurable volume change (Armer *et al.,* 2016).

On physical examination inspection is used to assess the skin color, folds, tags, and moisture integrity are assessed with temperature, thickness and senses are considered on palpation, the body functions may be detected through vital sighs which become abnormal with disease progression. Other examinations include, arm circumference measurements, infrared laser perimetry, tissue bioelectrical, and impedance spectroscopy (Shaitelman *et al.,* 2015). After the initial assessment limb volume is measured in two-week subsequent visits. A tape measure is used to measure both limbs 10cm below or above the olecranon or the lateral epicondyle and 10% or more limb volume than the unaffected limb is used to make a diagnosis and determine the severity of lymphedema (Foldi *et al.,* 2021).

Water displacement incorporates measurements of limb volume by displacing its own volume, and not used when both limbs are affected (Shaitelman *et al.,* 2015). Hardened skin fold clipper porometer is used to assess trunk swelling, Tonometry measures tissue resistance to electrical current to evaluate the fluid volume and determines the extent of tissue. A drawback to this method is that is expensive and only used in unilateral lymphedema(Armer *et al.,* 2016).

Other quantitative measures include an electronic volumeter and other subjective measures involve assessing pitting by applying pressure on different parts of the affected area or use stemmer's sign which shows positive results when the skin is thickened and cannot be pinched (Molica *et al,* 2014). After classification according to the etiology Staging is necessary based on the findings to allow for an objective assessment and at the same time plays an important role in planning appropriate interventions and evaluations of the outcome (Armer *et al.,* 2019).

WHO Lymphedema staging is in four steps. Stage 0 there are no symptoms ,the patient is at risk for months or years before developing active lymphedema but studies have indicated that it is possible to be identified by bio impedance and treatment given before moving to the next step. Stage one mild symptoms are present and can be improved by limb elevation. In stage two (moderate) pitting is absent, the tissue becomes increasingly firm because of fibrosis and increases the risk of further hardening and infection.

According to the International Society of Lymphedema (ISL), (2013) Stage three (severe) is the most advanced stage with increase in volume, the limb becomes very large and the skin takes a wrinkled appearance but it's rare in patients with breast cancer. Severity between the extremities. is estimated by the increase in volume, thus, these stages mostly indicate the physical condition of lymphedema.

In conclusion, lymphedema diagnostic methods vary, each with its own appropriateness for application in clinical practices. consequently, assessment methods need to be carefully selected depending on the clinical setting in consideration to accessibility, the cost involved as well as the patient outcome.

### 2.3.3 Treatment of Lymphedema

The goals of treatment are to stimulate the flow of lymph fluid, reduce the size of the limb and prevent further accumulation (Hayes *et al.,* 2016). Patient's educated about lymphedema help them understand activities their condition and strategies that control it ( Krok-Schoen *et al.*,2015).They are advised to avoid risks for inflammation or infection to the tissues where the most vulnerable being the skin, intravenous lines, blood draw from the affected limb or tattoos and to wear gloves when gardening.

Complete decongestive therapy (CDT) is the most recommended treatment strategy (Shaitelman *et al.*,2015). The initial four-week program include manual lymphatic drainage, multi layered short stretch compressing bandages exercise and proper skin and nail care to prevent infection (NLN, 2017). Phase two is the maintenance of the achievements of phase one conducted at home by the patient and requires family support. It involves continuous skincare, simple exercise, manual lymphatic therapy and use of compression sleeve and gloves during the day and compression bandaging during the night. (Armer *et al.,* 2019).

Manual lymphatic drainage is a massage applied gentle and slowly to correspond with naturally rhythmic lymphatic pulsation that stimulates lymph vessels to contract and directs fluid towards adjacent lymph vessels (Shaitelman *et al.*, 2015). Bandages are then applied immediately from the fingers to the axilla in layers to create high pressure gradient at the most distal part of the limb that gradually decreases pressure proximal to the limb (Parisot *et al.*,2015).

Skin care includes protecting exposed skin with sunscreen, keep the clean and dry, then patient educated on avoiding puncture to the skin as much as possible to prevent injury that may further Couse infection. And finally exercises with garments or bandages on, improve the flow of fluid (NLN, 2017). Combination of treatment modalities produced significant reduction in the total arm volume, as well as significant symptom improvement (Sierla *et al.*,2013).

**Plate 2.2 Compression Bandages**

### 2.3.4 Surgical Management

surgical management such as lymph node transplant is carried out on selected patients with long term complications whose trial on none operative management has failed Wamalwa *et al., (*2019) reported that between 2014 to 2017 only twenty patients underwent lymph node transplant in both public and private hospitals including Kenyatta National Hospital, Nairobi West Hospital, and Aga Khan University Hospital) to improve symptoms of patients with stage two lymphedema who do not respond to none surgical interventions. under the care of only two plastic surgeons that were available at that time that indicates lack of qualified specialties in most hospitals. Response to treatment is likely to vary between individual related factors example affordability and adequately trained health professionals in regional areas (Finnane *et*

*al.,* 2015). Effectiveness of Treatment is measured by changes in the limb volume and participants self-reported outcomes om symptom improvement (Singh *et al.,* 2016).

### 2.3.5 Factors Influencing the Management of Lymphedema

The goal of treatment depends on the physiologic functioning of the lymphatic system and presentation of the symptoms, the patients' choices of treatment , respect for the patients choices, setting priorities of care (Cohen *et al.,* 2001). In clinical practice, treatment options depend on patient's medical history, cancer status, symptoms, preferences, insurance coverage/financial status response to treatment and outcome may be influenced by the disease factors and patient's factors (Herrmann *et al.,* 2014).

### 2.3.6 Disease Factors

The disease related factors are the demand placed on an individual by a disease state, influence on adherence and the presence of additional co-morbid illness. Lymphedema reduces the ability of the limb to function normally due to obstruction that leads to edema predisposing the patient to the risk of developing cellulitis and deep venous thrombosis, in patients with severe disease the level of disability is increased which negatively influence patient adherence to the treatment regimen (Eyigor *et al.,* 2015). Many used cancer drugs have side effects that can compound the existing swelling ,ex steroids reduce mobility and function that affect the patient negatively (Ayre & Parker, 2019). The fungating lesions assess may be restricted due to the severity of the swelling and reduce mobility of the shoulder and Exudate may be increased if compressions is applied to the limb (Armer *et al.,*2015).

### 2.3.7 Patient Factors

Patients with lymphedema have a varying degree of functional impairment and response to therapy intervention will depend on multiple factors including knowledge level, attitude, belie, past illness and treatment experiences. Believes include the perceived risk of the condition worsening and their ability to treat it (Bormans *et al.*,2018).These beliefs may be influenced by their understanding about lymphedema, The patient's motivation to continue complexed treatment strategies may be influenced by trusted health professionals and patients coping mechanism, (Finnane *et al.*, 2015).

The size and shape of the limb plays an important role in choosing compression ready to wear and custom-made garments, psychological support is also a very important in management of lymphedema as it has the potential to motivate patients by influencing their ability to perform tasks and have expectation for success and self-care (Eyigor *et al.*, 2015). Responses to treatment vary between individuals' availability, accessibility and affordability of compression garments (Armer *et al.*, 2016).

Health care providers use patient's reported symptoms to diagnose lymphedema and making appropriate treatment decisions. Pain, psychological, and physiological aspects may also be used (Armer *et al.*,2016). Compression garments is a constant reminder of the disease lead to low self-esteem, causing anxieties and making privacy issues more difficult (Armer *et al.*, 2016).

In old age other comorbidity conditions are present and increase the severity of the disease (Eyigor *et al.*, 2015). Lymphedema predisposes to infection (Armer *et al.*, 2016). According to the ISL (2013), other factors that predict a successful outcome include encouraging the patient to maintain normal body weight. Patients for surgery

needs selected carefully and counselled to ensure realistic expectation of likely outcome and when patients are on intermitted pneumatic compression should be used with caution in peripheral neuropathy, when there is pain and numbness, skin grafts and when the skin is fragile.

### 2.3.8 Treatment Factors

The cost, discomfort associated with treatment, symptoms and garments availability can be a burden and affect the treatment options (Denlinger *et al.,* 2014). Adherence to prescribed treatment may be compromised, healthcare providers transfer of knowledge and skill for self-management and the organization of follow up care also influencing treatment (Finnane *et al.,* 2015).

### 2.3.9 Health System Factors

The health of the patient is determined by social. economic, cultural and physical environments. These factors come from system levels (inside and outside the organization and include, legislation, policies, culture, people, policies processes and resources. The health care systems support primary care in cancer diagnosis by quick and easy access to investigations and is also a factor in timeliness cancer diagnosis (Katzel *et al.,* 2014).

The health system factors describe the interaction between the patient and the healthcare delivery team, these include inter personal relationship between the patients and the healthcare team, the ability of the healthcare team to impact knowledge, adequate assessment skills, feedback on performance and to establish follow up contact. There is evidence that good interpersonal relationships than improve adherence to treatment regimen and poor relationship the likelihood to adherence (ISL, 2013). Healthcare providers education, labor agreements, workforce trends, skills,

staff experience communication and governance are key in prioritizing patient's plan of inclusion of the patient and family in decision making and care allows them to acquire the skills to perform tasks either as patients or careers (Shaitelman *et al.*,2015).

## 2.4 Treatment Outcome for Lymphedema

The goals of lymphedema treatment outcomes are to decongest the limb by fluids reduction and associated tissue, prevent complications and reoccurrence. Effective treatment is likely to improve symptoms for patients and reduce health costs (Hayes *et al.*,2016). Findings from lymphedema treatment research suggests that when diagnosed and treated early treatment outcome are optimal (Finnane *et al.*, 2015).

Adherence to any form to treatment presumes adulate recourses including funding and the financial status of the patient, staff turnover policies and practices. Patient with limited access to supplies or non-reimbursable by third party players or people with other comorbidities may be at risk of developing a more severe disease. Geographical location such as distance away from hospital and family support is also a setback to patient management, lack of resources and financial support for supply by insurance companies limit the use of available machines used for diagnosis while Culture determines the patient's acceptance for care (Michelini *et al.*, 2018). The likely hood that the patient's adherence to the prescribed treatment may be compromised if the distance from the health facility is far and the patient is subjected to long time travel (Finnane *et al.*, 2015). The cost involvement can be a burden for people with law income (Denlinger *et al.*,2014).

The majority of lymphedema treatment studies stated the importance of continuous assessment as an objective measure help evaluate the efficiency of the treatments, and motivate the patients and their therapist (Finnane *et al.,* 2015). According to Palya *et al.,* (2018), measuring the result of lymphedema treatments is important because regularly applied measuring methods help to evaluate the efficiency of treatment , motivates the patients and their therapist.

### 2.4.1 Morbidity and Mortality of patients with lymphedema

Lymphedema is a disease of low mortality and high morbidity, it has mild, moderate, severe and chronic phase of clinical manifestation(WHO,2013). The mortality of patients with lymphedema in breast cancer is related to the severity of symptoms as a result of late diagnosis allowing progression of disease that evolve and facilitate death (Josecili *et al.*,2019). In another study the findings show that women with breast cancer lymphedema die more of cancer than those without lymphedema (American Cancer Society, 2016).

## 2.5 Summary of Literature Review and Research Gap

There were no studies on lymphedema secondary to breast cancer in Kenya. one study looked at lymphedema in HIV patients (Park *et al.,*2018).Data on knowledge of lymphedema in developing is limited(Jacques *et al.,* 2018).For these reasons there was need to evaluate lymphedema management outcomes and their determinants among patients treated with breast cancer in selected hospitals in western region (Jacobs *et al.,* 2020).According to the literature, clinical management strategies and did not involve healthcare providers interventions despite the benefits of the healthcare providers role in assessment, diagnosis and treatment overlooked limb assessment which is essential in monitoring of the progress of the patient. Some studies used none

probability sampling. the studies were carried out in specific counties and smaller samples were used indicating that the bulk of results could not be generalized. To fill into the gap, the researcher included healthcare providers and patients, used probability sampling and more counties were used to make inferential with the hope that findings will not only benefit the selected counties but the entire country , build the capacity to care for lymphedema patients and improve their quality of life.

# CHAPTER THREE

# RESEARCH METHODOLOGY

## 3.1 Overview

This chapter describes, the research design, study area, target population, sampling method, sample size, inclusive criteria, exclusive criteria and development of research instruments.

## 3.2 Research Design

Cross sectional analytical study design guided the conduct of this study using both quantitative and qualitative and data collection methods.

## 3.3 Study Area

The study area covers a total of thirteen counties namely Kisumu, Homabay, Kisii, Nyamira, Siaya, Migori, Bungoma, Vihiga, Busia Kericho, Bomet, Trans-Nzoia and Kakamega. The region borders Uganda to the wests and is west of the eastern rift valley wall of the Mau and Elgeyo escarpments (Demographic, 2014). In this region more than 80% women with breast cancer present at a late stage and are put on aggressive treatments that are described as a major cause of lymphedema (Tororrey *et al.*,2012). The study was conducted in selected health facilities offering comprehensive cancer screening and provide cancer treatment either as a stand-alone facility providing (chemotherapy, radiotherapy, or surgical oncology) or offer preventive, screening, early detection, diagnosis and registration according to the ministry of health guidelines) 5(30%) of health facilities were selected by simple random sampling .

This is according to Mugenda and Mugenda (2003) that a sample size of 30% is a good representation of the target population. these included Bungoma(n=33), Siaya (n=29), Kakamega (n=48). Bomet (n=38) and Kisumu County referral hospitals (n=41).

Bungoma county is one of the 47 counties in the republic of Kenya, its divided into 9 counties namely Bumula, Kanduyi, Sirisia, Kabuchai, Kimilili, Tongaren, Webuye west, Webuye east and mount Elgon. Bungoma county borders the republic of Uganda to the west, Busia county to the south west, Mumias to the south and Trans-Nzoia and Kakamega to the north east. The county has an area of 3.032.2 sq, km and lies between 1.200 to 1.800 meters above sea level and experiences mean temperature of 23degrees centigrade its latitude stands 0.57 with the longitude of 34.56 the population is estimated at 1,670,570 of which 812,146 are males and 858,389 are females as per 2019 census. the county experiences high level of rainfall and is a home of many rivers which are used for small scale irrigation, the main economy is agriculture. The county has 11 hospitals, 19 health centers 96 dispensaries and 198 clinics. The county offers cancer treatment most common being breast cancer.

*Bungoma County Referral Hospital* is a governmental health facility located in Bungoma town along Kanduyi- Mumias road it's a level 4 hospital with the bed capacity of 216 and services offered include inpatient and inpatient services, specialty services that include Ear nose and throat, ophthalmology, screening and pathology and high level medical surgical services and serves a population of 2 million people.

*Jaramogi Oginga Odinga Teaching and Referral Hospital* is a level 5 and a major teaching hospital it is situated in Kisumu city, it serves a population of about 5 million people, it is located about 3.5 miles from Kisumu city between Kondele and Kibuye along Kisumu- Kakamega high way. It serves counties, sub counties and private

hospitals in more than 10 counties. Screening of cancer is free in this facility; biopsy processing is available at the facility in room 16. it is noted that residents turn to the hospital when the cancer is advanced and in the period of 12 moths out of the patients screened for breast cancer 55.8%were confirmed positive.

*Bomet county referral hospital* is a governmental hospital in Bomet county, it is located in Longisa off Bomet road. it's a level 4 hospital with the bed capacity 144, overs 24 hours of emergency services, inpatient and outpatient services, Intensive care unit, casualty, accident and emergency and produces 800 liters of oxygen. The count department of medical services and public health in collaboration with the ministry of health established a chemotherapy unity at Longisa hospital because of the ongoing activities on cancer screening and palliative care services, the count has expanded the range of services by incorporating radiotherapy unit, the unity is managed by highly trained and skilled staff on oncology such as nurses, clinical officers, medical officers, physicians and pharmacists among others. the county records between 200 to 299 cancer cases annually among them esophageal cervical and breast cancer,

*Siaya county referral hospital* is a level 4 hospital with the bed capacity of 200 situated in Siaya town serving an extremely rural living people, it's close to Uganda and Lake Victoria borders and covers an area of 2.529.8km2. According to the 2019 census the population served by this hospital was 993.183 with the population density of 393 people per km2.Apart from the general level 4 services provided the county hospital has 98 healthcare providers who provide cancer screening and the positive cases are about 200 annually.

*Kakamega county referral hospital* Kakamega is a level 5 in the health delivery systems in Kenya. it is located 500m off Kisumu Kakamega highway it is 55km away from Kisumu city and its situated north of Kakamega town, Kakamega county. The county lies on 30,020km2, borders Vihiga County to the south, Siaya County to the west, Bungoma and Trans Nzoia Counties to the north, and Nandi and Uasin-gishu Counties to the east (KDHS,2014).The facility serves as a main referral hospital for a total population of 1,867,579 as well as the neighboring counties including Vihiga, Bungoma and Busia has a bed capacity of 449, has medical, surgical words numbered 1to10 offers maternal child services, intensive care .Ear, nose and throat, ophthalmology and oncology deportment among others the oncology department offers screening , diagnosis and treatment of cancer. Breast cancer is the most prevalent cancer among women where125 new cases were diagnosed between January to December 2018 and commenced on treatment.

### 3.4 Study Population

192 healthcare providers working in oncology units of Kakamega County Referral Hospital(n=48). Jaramogi Oginga Odinga Teaching and Referral Hospital (n=41). Bungoma County Referral hospital (n==33). Siaya County Referral hospital (n=29). and Bomet County Referral hospital (n=38) Participated in the study. They included doctors, clinical officers, nurses, physical therapists. nutritionists and occupational therapist. Also included were 192 patients with breast cancer related lymphedema.

### 3.5 Inclusion and Exclusion Criteria

#### 3.5.1 Inclusion criteria

i. Healthcare providers providing direct care to patients with breast cancer , that is, nurses, doctors, clinical officers, nutritionists, physical therapists and occupational therapists

ii. Health care providers who must have worked in the oncology units for more than six months.

iii. Health care providers willing to be included in the study, agree to sign the informed consent and are present during data collection.

iv. All patients with the primary diagnosis of breast cancer with lymphedema available during the period of data collection.

#### 3.5.2 Exclusion criteria

i. Healthcare providers who did not consent to the study.

ii. Patients with Breast Cancer Related Lymphedema (BCRL), not willing to participate in the study.

### 3.6 Sampling procedure

This study was carried out in western region because breast cancer is more prevalent with different counties reporting 200 to 300 new cases annually and more than 80% patients show up at a late stage and are put on aggressive treatments that are described as a major cause of breast cancer related lymphedema (Torrorrey *et al.*,2012).

Purposive sampling was used Level 4 and above hospitals in western region due to their capacity to provide cancer treatment modalities either as a stand-alone facility providing (chemotherapy, radiotherapy and surgical Oncology unity) or offer

preventive, screening, early detection diagnosis registration and treatment according to the ministry of health guidelines for establishment of cancer management centers in Kenya (2018). 30% of the selected hospitals were randomly selected to participate in the study. This is according to Mugenda and Mugenda (2003) that a sample size of 30% is a good representation of the target population. Healthcare providers were chosen using random sampling technique. A list of healthcare providers working in cancer centers of each hospital was obtained and those who met the inclusion criteria were given numbers depending on the required number at each hospital. The selection was done randomly depending on the number required at each healthcare facility based on the on the proportionate sampling table. Convenience sampling was used to pick patients who met the inclusion criteria and who were available during the period of data collection.

**Table 3.1 Healthcare providers for each facility**

| Health facility | Healthcare providers population | Healthcare providers Sample size |
|---|---|---|
| JOOTRH | 137 | 41 |
| Siaya | 98 | 29 |
| Bungoma | 110 | 33 |
| Bomet | 137 | 41 |
| Kakamega | 160 | 48 |
| Total | 642 | 192 |

The patients sample was arrived at by observing healthcare providers give one on one care in each health facility, and were given numbers to avoid repetition.

**Table 3.2 Patients for each facility**

| Bungoma | Kakamega | Siaya | Bomet | JOOTRH |
|---|---|---|---|---|
| 33 | 48 | 29 | 41 | 41 |

### 3.6.1 Sample Size Determination

The minimum number of healthcare providers for the study was determined by fisher's formula because the health care providers who give care to the cancer patients are limited.

Formula $n = \frac{Z^2 pq}{d^2}$

n= the desired sample size (if the target population is >10,000).

Z=The standard normal deviation at the required confidence level of 95% (equivalent to 1.96)

P=The proportion in the target population estimated to have the characteristics being measured

(Set at 0.05 = -+5) -

Since the proportion of the population with the characteristics is not known then 50% choice of respondent is used as recommended by Fishers *et al*, (1983), Mensa, (2020). $d^2$=The percentage of picking or response choice of 50% = 0.5

q = 1-p

The confidence interval

$$N = \frac{(1.96)2(.50)(.50)}{(.50)2} = 384$$

Since the target population is less <10,000 then the required sample size was smaller thus adjustment done using the following formula

nf= n

---

1+n/N

Where fn = the desired sample size for the population<10,000

n=the calculated sample which is =384

$$fn = \frac{384}{1+(384/384)}$$

$$= 384/1+1=192$$

Therefore, the desired minimum sample size was 192 **.**

**Table 3.3 Proportion of samples**

| **Target population** | **Tool** | **Total sample** |
|---|---|---|
| Healthcare providers | Questionnaire<br>Observation checklist<br>Focus group discussion | **192** |
| Patients with Lymphedema | Questionnaire | **192** |

**Table 3.4 Health Care Providers' Sample distribution**

| **Health facility** | **County** | **Doctors** | **Clinical officers** | **Nurses** | **Others** |
|---|---|---|---|---|---|
| JOOTRH | Kisumu | 2 | 6 | 30 | 3 |
| Siaya county referral hospital | Siaya | 1 | 4 | 24 | - |
| Bungoma county referral hospital | Bungoma | 3 | 10 | 20 | - |
| Longisa county referral hospital | Bomet | 2 | 8 | 28 | 3 |
| KCGRH | Kakamega | 6 | 3 | 24 | 15 |
| | Total | 14 | 31 | 126 | 21 |

### 3.7 Data Collection Tools

Data was collection tools used in the study were previously validated by the international lymphedema network (ILF) and modified to suit the study. These tools included structured questionnaire for healthcare providers at each selected hospital where healthcare providers picked from among others, the correct responses from a list of responses for each- question as described in the attached questionnaire (See Appendix II). Observation checklist to assess healthcare providers skill on lymphedema care provision (See Appendix III). FGDs used to obtain information on patient care interventions from shared expediencies and expertise, and structured questionnaires to assess the outcome of patient treatment (See Appendix VI).

#### 3.7.1 Structured questionnaires for healthcare providers

The questionnaires were written in English, which contained closed ended questions and assessed the following variables, Socio demographic characteristics related, sex, age group, professional qualification, and education, the tool also consisted of items applying the Likert scale with the responses ranging from strongly agree(4) agree(3) disagree(2) strongly disagree(1) that describes the opinions of the participants, An optimal section comprising of multiple choice questions were used to test the actual knowledge of nature and scope of lymphedema and clinical management, these responses were then marked against a validated marking scheme. The total scores weight against 100% and recorded as appropriate according to the nursing council of Kenya.

#### 3.7.2 Structured questionnaire for patients

The patient questionnaire assessed the demographic variables, breast cancer treatments, time taken to develop lymphedema, lymphedema treatment and Likert's

scale used to measure the outcome of lymphedema treatment by the participants reporting how much the treatment helped in improving symptoms.

### 3.7.3 Clinical assessment and observation checklist for healthcare providers

The observation checklists comprised of 7 items which included history taking, physical examination and diagnosis of lymphedema, investigations to confirm the diagnosis, the patient's level of activity assessment and management. Health education, complication assessment, monitoring and follow up of hospital appointments**. Yes** was used for healthcare providers who competently performed the required procedure and **no** for those who either skipped the procedure or failed to perform the procedure as required. This was done by the research assistants observing healthcare providers, provide care without them realizing that they are being observed from the point of the patient's entry through to exit.

### 3.7.4 Focus Group Discussion for Health Care Providers

Five groups were used one at each facility with 4-8 members who were conveniently selected and data collected by voice and notes recording by the principal researcher. According to (Stewart & Shamdasani, 2014) FGD is used by people with the same characteristics to share the experiences, competencies and expertise. The participation was voluntary and facilitated a broad insight into areas that may not be clarified on individual perspective, in dealing with lymphedema in breast cancer patients among healthcare providers guided by questions on knowledge and skills and strategies used in lymphedema management for shared and change of perception to better manage the patients and enable better patient outcome.

### 3.8 Validity and Reliability of the instruments

A pre test was carried out at Vihiga County Referral Hospital prior to the actual data collection period and appropriate adjustment were made to ensure usability and generalizability of the instruments, a representative sample of 20 healthcare providers and 20 breast cancer patients were chosen from the population of study, questionnaires were edited before the actual data collection and the completed questionnaires were scrutinized to check if the questions were understandable, answers during pre-test and those given during the actual data collection were compared to assess the likely response of the instruments. In order to eliminate errors, the researcher collected data from healthcare providers who had worked in the centers for more than six months and the research assistants were qualified so that the consistent way of asking and answering questions was developed and Cronbach's alpha test on the checklist used in the study yield over 70% which was acceptable.

### 3.9 Data Collection Procedure

Data was collected from 24th June to 24th July 2021. The information was collected from one hundred and ninety-two healthcare providers and one hundred and ninety-two patients. The study team comprised of the researcher and the research assistants who underwent a day's training and were trained on understanding the questions in the tool, identifying the participants in the inclusion criteria, explained how to collect information using the available tools and assigned at the selected areas. The participants signed informed consents, data tools included a self-administered questionnaire, an observation check list and focus group discussion, the questionnaire had parameters to test the actual knowledge of nature and scope of lymphedema and clinical management and an observation checklist was used to observe and evaluate healthcare providers competence in history taking, physical examination, investigation

assessment and diagnosis the use of skills in carrying out procedures in patient management without prior arrangement. 192 patients who consented also filled the questionnaires which were collected by the researcher at the end of each day.

### 3.10 Pre-testing

Prior to the actual data collection, pre-testing was carried out at Vihiga county referral hospital on 20 healthcare providers (10% of the total population) and 4 patients. The hospital was chosen because it had the same characteristics with other selected hospitals and the tool's validity and reliability checked by the principal investigator where , questionnaires were edited before the actual data collection and the completed questionnaires were scrutinized to check if the questions were understandable, answers during pre-test and those given during the actual data collection were compared to assess the likely response of the instruments. To ensure that data analysis technique matched expected responses corrections were done on the spot and at the end of each field day.

### 3.11 Data Analysis

Obtained data was verified and entered into Microsoft excel and Analysis was done using statistical package for social science software (SPSS) version 23.1 as per the objectives of the study. descriptive and inferential statistics were used both the median and the mean of 192 healthcare providers who answered questions were determined, the t-test was applied to test mean difference of scores between two categories while one-way ANOVA test was applied to test differences of more categories.

#### 3.11.1 Model Assumptions

Since the mean and the median were almost equal, normality was assumed and hence Linea regression method was used. Bivariate regression was used to test the strength

of association and the relationship between variables, demographic variables showed professional qualification and age as significant factor that influenced knowledge. Particularly clinical officers and medical officers were 11 and 17 times higher in scores compared to nurses (Coeff=11.6; ci:5.1-18.2, p-value=0.001and Coeff= 17.7:ci=8.2-27.2p-value<0.001and therefore p-value below 0.05 was considered as level of significance.

Descriptive tables were used to show level of agreement from self-reported knowledge assessment survey that ranged from strongly agree, agree to disagree and strongly disagree. Cronbach's alpha was finally applied to show the internal consistence of the reported results. A value of between 0 and 1 was used to show the coleration where value >0.7 showed a stronger coleration and hence consistency while value<0.3 showed weaker coleration and hence consistence and values between 0.4 and 0.6 showed neutral results, descriptive tables were also used for demographic variables of 192 patients, similarly the median and the interquartile ranges were determined.

### 3.12 Qualitative data analysis

Five focus group discussions were held, one in each facility with 4-8 members of health care providers conveniently selected to attend each group. focus group data was thematically analyzed based on the work of Miles & Huberman (1994) as shown in figure 3.1 and the possess was summarized guided by questions on knowledge, skills, strategies used in management.

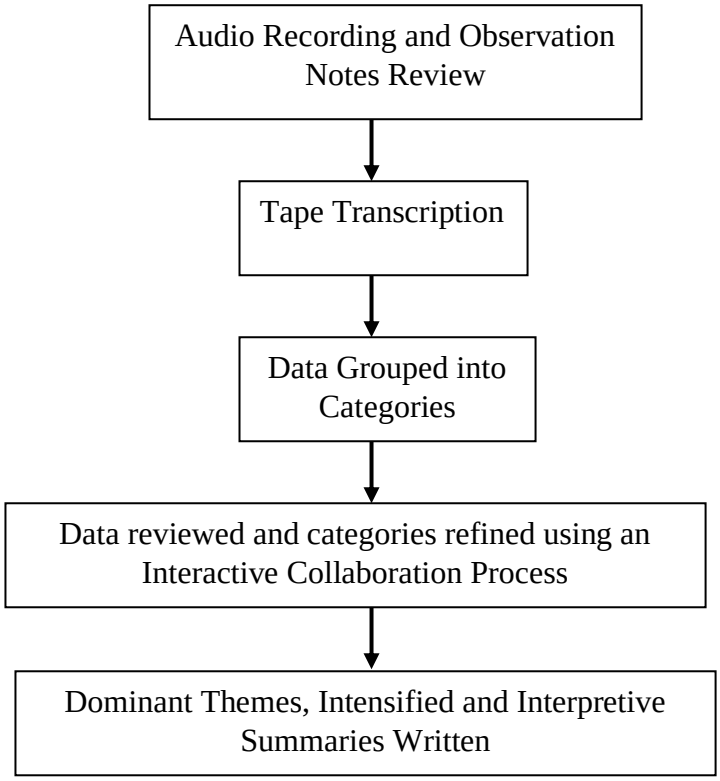


**Figure 3.1 Focus group Analysis Flow Chart**

### 3.13 Ethical Considerations

To ensure the rights of participants are safeguarded, the researcher adhered to ethical and legal guidelines for the conduct of research. Issues considered included, informed consent, confidentiality, safety, autonomy, justice, beneficence and non-maleficence. The respondent's participation was voluntary, they were assured that no information would be shared by unauthorized persons but only for the purpose of the study.

Approval to carry out the study was sought from the directorate of postgraduate studies, institute and research ethical committee (IREC) Masinde Muliro university of science and technology, National commission for science technology and innovations (NACOSTI), And approvals from five selected counties and county referral hospitals which included department of health and sanitation Kisumu county (GN/133VOLV11(122), Jaramogi Oginga Odinga teaching and referral hospital

(IERC/JOOTRH/463/21), County government of Siaya (SYA/CRH/SUP.COR/V1.49), CGS/CHD/RESEARCH/VOL.1V(108), County government of Bungoma (ref.CG/BGM/CDH/RESRC/VOL.1(87), County government of Kakamega (ref.cgk/ocs/gencrr/06/11), (ref.kaka/c/ga/29/17/vol.v/120). And county government of Bomet (Longisa county referral hospital) (ref. CGOB/MS/GCN, CORR/120). (See appendixes for approval documents)

### 3.12.1 Informed Consent

This principle applies to respect for human dignity, right to self-determination and right to full disclosure. This was fully granted by the researcher through the provision of relevant details of the topic, objectives, purpose and why the study was important and respondents were given an opportunity to choose and the consent signed prior to participation. this was captured in the informed consent (Appendix 1).

### 3.12.2 Confidentiality

The information provided by the respondents remained protected from disclosure outside the research setting and safeguarded in agreement with participants how their identifiable information was handled and disseminated. The participants were assured that the reports will be shared by Masinde Muliro University of Science and Technology and kakamega, Bungoma, Kisumu, Siaya and Bomet counties in support of healthcare providers development with the aim of improving management of lymphedema in Breast cancer patients

### 3.12.3 Privacy

The information obtained from the participants was safeguarded by researcher with No identification of study participants during data collection except for coding to identify the questionnaires.

### 3.12.4 Beneficence

The participants were informed that their participation did not have direct benefits but provide information to educationists and policymakers to come up with strategies that would help healthcare providers to better manage lymphedema.

### 3.12.5 Non maleficence

This entailed the use of obtained information to benefit others and no harm was done to the respondents by use of the obtained information during the entire prosses.

### 3.12.6 Justice

Fairness and equity were observed without discrimination and eligible respondents had an equal chance to participate in the study. This principle applies to the right to fair treatment and the right to privacy. The study ensured fair treatment by; carrying out a non-discriminatory selection of participants, adhering to the procedures outlined, giving the participants the researcher's contacts to allow clarification of information at any time in the study and ensuring respectful and courteous treatment at all times. Right to privacy was achieved through anonymity by ensuring the names of the participants are not written on the questionnaires except the codes. This kept the information anonymous and no links were made to the informants.

# CHAPTER FOUR

# RESULTS

## 4.1 Overview

This chapter presents the results of this study guided by specific objectives.

1. To assess the competence of healthcare providers in clinical management for lymphedema secondary to breast cancer treatment.
2. To examine effectiveness of strategies used in the management of lymphedema secondary to breast cancer treatment.
3. To determine the outcome of lymphedema patients' management.

## 4.2 Socio demographic characteristics of healthcare providers

Table 4.1. Shows the demographic characteristics of study participants, a total of 192 Healthcare providers participated in the study registering 100% response rate. Most of them were female, 117 (60.9%), most frequent age ranged from 31-34 years of age, 46 (24.0%). A higher response was observed among nurses, 126 (65.6%) and majority of the respondents were diploma/certificate holders 117 (60.9%).

**Table 4.1 Socio demographic characteristics of healthcare providers**

| Variable | Frequency (n) | % |
|---|---|---|
| gender | | |
| Male | 75 | 39.1 |
| Female | 117 | 60.9 |
| Age group | | |
| Below 24 years | 25 | 13.0 |
| 25-30 years | 43 | 22.4 |
| 31-34 years | 46 | 24.0 |
| 35-40 years | 19 | 9.9 |
| 41-44 years | 21 | 10.9 |
| 45-50 years | 7 | 3.6 |
| Over 51 years | 31 | 16.2 |
| Professional qualification | | |
| Nurse | | |
| Clinical officer | 126 | 65.6 |
| Medical officer | 31 | 16.1 |
| Oncologist | 12 | 6.2 |
| Others | 2 | 1.0 |
| | 21 | 10.9 |
| Education | | |
| Diploma/certificate | 117 | 60.9 |
| Bachelor's degree | 66 | 34.4 |
| Masters | 8 | 4.2 |
| Doctorate | 1 | 0.5 |

### 4.3 Socio demographic characteristics of patients

Table 4.2 shows the sociodemographic characteristics of 192 patients who participated in the study who were all females. The ages ranged from 43-60 (IQR=43-60) with the median of the patients was 53.5 . Most of them were self-employed, 96 (50.0%), were married, 113 (58.9%), most were Christians, 157 (81.8%) and most of them received chemotherapy amongst other treatments for breast cancer. The median time taken to development lymphedema symptoms after breast cancer diagnosis was 12.5 months (IQR=8.1, 22.8).

**Table 4.2 Socio-Demographic characteristics of patients**

| Variable | | Frequency, N= 192 | (%) |
|---|---|---|---|
| Age | Median | 53.5 | |
| | IQR | 43, 60 | |
| Occupation | | | |
| | Employed | 35 | 18.2 |
| | Self-Employed | 96 | 50.0 |
| | Retired | 44 | 22.9 |
| | Others | 17 | 8.9 |
| Marital status | | | |
| | Single | 26 | 13.5 |
| | Married | 113 | 58.9 |
| | Widowed | 52 | 27.1 |
| Religion | | | |
| | Christian | 157 | 81.8 |
| | Muslim | 35 | 18.2 |
| Time in months taken in development of lymphedema symptoms (Median, IQR) | | 12.5 (8.1, 22.8) | |

### 4.4 Healthcare providers' competence in clinical management of lymphedema secondary to breast cancer treatment

The results include health care providers knowledge on management of lymphedema, the association between demographic variables and knowledge, self-reported knowledge and results of skill assessment.

#### 4.4.1 Health care providers' knowledge on clinical management of lymphedema

This section provides results on assessment of healthcare providers knowledge on lymphedema in breast cancer patients. The questions are described in the attached questionnaire, several areas were examined which included, history taking, physical examination and treatment aimed at assessing knowledge on lymphedema management among healthcare providers and grades awarded according to the nursing council of Kenya grading system 75-100% distinction. 65-74 Credit, 50-64 pass. 49 and below fail.

### 4.4.2 The overall score graded as Distinction, Credit, Pass, or Fail

Most healthcare providers who scored 50% and above were 166(86.5%) while 26(13.5%) failed

**Table 4.3 The overall score graded as Distinction, Credit, Pass, or Fail**

| Grades | category | n | % |
|---|---|---|---|
| Distinction | 75-100 | 37 | 19.3 |
| Credit | 65-74 | 42 | 21.9 |
| Pass | 50-64 | 87 | 45.3 |
| fail | 49 and below | 26 | 13.5 |
| Total | | 192 | 100 |

### 4.4.3 Knowledge of lymphedema management per specific questions

A total of 10 multiple choice questions were asked and findings shown in Table, confirm the level to which respondents know about lymphedema management; those who had knowledge in important areas of lymphedema management such as skin care (OR = 0.56, p = 0.01). stoking class, A pressure (OR = 1.841, p = 0.004). positive stemmers sign test (OR = 2.717, p 0.001) were less likely to get distinctions. Those who knew a sentinel node as the first lymph node that drain the body(OR = 2.249, p = 0.003) and early detention and intervention as the best to reduce and manage lymphedema were (OR = 0.235, p = 0.016) were statistically significantly more likely to have a distinction grade than those who didn't know. Most participants were above average but with deficit of knowledge in important areas of practice in lymphedema management such as skin care, stoking application and diagnosis with over 50% getting incorrect answers.

**Table 4.4 Individual knowledge of lymphedema management**

| | | Total n (%) | OR(CI) | P-value |
|---|---|---|---|---|
| 1.The importance of skin care for people with lymphedema | Correct | 67 (34.9%) | 0.567 (0.390-0.882) | 0.001 |
| | Incorrect | 125(65.1%) | | |
| 2. Lymphedema stoking class A pressure | Correct | 66 (34.4%) | 1.841 (1.215–2.791) | 0.004 |
| | Incorrect | 126(65.6% | | |
| 3. The most appropriate initial management for lymphedema | Correct | 82 (43.0%) | | |
| | Incorrect | 110(57%) | 3.462 (2.230–5.375) | 0.001 |
| 4. Positive stemmers sign test | Correct | 113(59.0%) | 2.717 (1.640–4.501) | 0.001 |
| | Incorrect | 79(41%) | | |
| 5.A sentinel node is the first lymph node that drain the body | Correct | 129(67.0%) | 2.249 (1.321–3.831) | 0.003 |
| | Incorrect | 63(33.0%) | | |
| 6.Patients who do not have symptoms within two years are no longer at risk of developing lymphedema | Correct | 134(70.0%) | 1.210 (0.824–1.776) | 0.331 |
| | Incorrect | 58(30.3%) | | |
| 7.Early detection and intervention to reduce and manage lymphedema | Correct | 164(85.4%) | 0.235 (0.072–0.765) | 0.016 |
| | Incorrect | 28(14.6%) | | |
| 8. True statement about lymphedema | Correct | 149(78.0%) | 0.323 (0.212–0.491) | 0.001 |
| | Incorrect | 43(22%) | | |
| 9.Milroy's disease | Correct | 86 (45.0%) | 0.953 (0.607–1.497) | 0.834 |
| | Incorrect | 106(55%) | | |
| 10 How treatment effectiveness is measured. | Correct | 164 (85.5%) | 5.7(2.5-6.3) | 0.023 |
| | Incorrect | 28(14.5%) | | |

### 4.4.4 Findings on skill assessment

An observation checklist was used to assess skill competence by direct observation. In broad categories, this included history taking, physical examination, investigations, physical activity, patient education, complication assessment, and monitoring and follow up. Skill demonstration by healthcare providers in history taking, assessment diagnosis, treatment and follow-up of lymphedema was assessed by direct observation. A scoring system of yes or no was used for all the procedures done and table 4.4 shows

better performance was observed in history taking and physical examination and vital signs assessment with over 70%. ability to assess any symptoms present (63.6%) and identifying the needs for patients with lymphedema had an average response of 59.1%. while assessment of limb volume had a Low response (27.3%) an indication that the limb volume procedure was not practiced by most respondents.

Healthcare providers were 1.6 times more likely to take history of chief complains, medical history and history of lymphedema and the treatment type OR;1.6:CI:1.0-2.4; p value =0.037. 3.6 times more likely to carry out systemic and symptom assessment OR;3.6CI:1,5-6.7: P Value = 0.039, 4.9 times more likely to take vital signs OR;4.9:CI:2.0-7.4 P Value =0.002. 0.4 times more likely to carry out symptoms assessment OR 0.4:CI:0.1-1.9 P Value = 0.004, 5.4 more likely to educate the patient modifiable risk factors and signs and symptoms.OR;5.4; CI;2.4-9.3,P Value =0.022

Finally, A Cronbach's alpha was applied to show the consistency of the reported results. A value of between 0 and 1 was used to show the correlation where value >0.7 showed a stronger correlation and hence consistency, while values <0.3 showed weaker correlation. The Cronbach's alpha of 0.668 in history taking skill and 0.730 in physical examination showed that they were the mostly applied procedures by the respondents in the management of lymphedema and a Cronbach's alpha value of -0.9011 showed vital information about patient self-care , complication assessment and when to come back for the next visits were not practiced across all health facilities.

**Table 4.5 Healthcare provider's skill assessment in clinical management of lymphedema (N=192)**

| Variable | Indicators | Procedure done (%) | Procedure not done (%) | OR(CI) | P-Value |
|---|---|---|---|---|---|
| | Chief complains | 44 (22.9) | 148 (77.1) | - | |
| History of lymphedema | Medical/Surgical history | 26 (13.5) | 166 (86.5) | 0.6(0.1-3.5) | 0.476 |
| | History of lymphedema and treatment type | 44 (22.9) | 148 (77.1) | - | - |
| Physical examination | Systemic assessment | 26 (13.5) | 166 (86.5) | - | - |
| | Symptom's assessment | 9 (4.7) | 183 (95.3) | 0.4(0.1-1.9) | 0.004 |
| | Systemic assessment & Symptom's assessment | 96 (50.0) | 96 (50.0) | 3,6(1.5-6.7) | 0.033 |
| | Vital signs (BP, RR, SPO, Pulse) only | 17 (8.9) | 175 (91.1) | 0.6(0.1-1.9) | 0.089 |
| | Weight, Height, BMI only | 17 (8.9) | 175 (91.1) | 0.6(0.1-1.9) | 0.089 |
| | Vital signs (BP, RR, SPO, Pulse) & Weight, Height, BMI | 131 (68.2) | 61 (31.8) | 4.9(2.0-7.4) | 0.002 |
| Investigations | Limb volume | 8 (4.2) | 184 (95.8) | - | - |
| Diagnosis | Identify the needs for patients with lymphedema | 44 (22.9) | 148 (77.1) | - | - |
| Physical activity | Current level of physical activity and any exercise | 113 (58.8) | 79 (41.1) | - | - |
| Patient education | On modifiable risk factors | 9 (4.7) | 183 (95.3) | - | - |
| | On risk factors, Signs and symptoms & Self-management | 52 (27.1) | 140 (72.9) | 5.4(2.4-9.3) | 0.022 |
| Complication assessment | Wound infection, and necrosis | 44 (22.9) | 148 (77.1) | - | - |
| Monitoring and follow up | Give next date of appointment | 113 (58.8) | 79 (41.1) | - | - |

Findings from focus groups discussion showed deficit of knowledge among healthcare providers by failure to clearly define lymphedema which must include what lymphedema is, the courses, risk factors and signs and symptoms indicated in extracts

below *"…..a swelling in one of the limbs either lower or upper due to the blockage of the lymphatic system…."* (Health care Provider C and D, FGD.1).

*"… just a swelling in the legs or arms…"* ( Health care provider k,FGD,3).

*"….reported one risk factor as history of surgery……"* **(**Health Care provider R,FGD,5), "….*Radiation Therapy because when the patient gets irradiated the radiation affects the lymphatic system because of the fibrosis that ultimately leads to blockage…."* (Health care provider D,FGD,1) and "…. *it depends on the stage of breast cancer, especially patients in late stage…."* (Health care provider c).

but the extract below best describes the diagnosis of lymphedema, "…. *it can diagnose by history taking, physical examination and limb volume assessment…. "* **(** Healthcare provider, FGD1).

### 4.5. Strategies used in management of lymphedema

The results represent patient's demographic characteristics, breast cancer treatment before developing lymphedema, time taken to develop lymphedema and treatment strategies for lymphedema.

#### 4.5.1 Breast cancer treatments before developing lymphedema

The patients who developed lymphedema were on different treatment modalities such as surgery, chemotherapy ,radiotherapy, hormonal therapy or the combination of two or more treatments at different intervals. Table 4.6 bivariate analysis shows the relationship between breast cancer treatment and development of lymphedema. The patients were 0.5 more likely to develop lymphedema after Surgery, Chemotherapy and Hormonal therapy,OR:0.5;CI;0.1-0.8, P Value =0.003, 0.1 times more likely to develop lymphedema after Chemotherapy Radiotherapy and Hormonal therapy OR;0.1;CI 0.0 -0.7, P Value = 0.042, 0.1 times more likely to develop lymphedema after Chemotherapy and Radiotherapy OR;0.1:CI; 0.0-0.8 P Value = 0.003, 0.4 times more likely to develop lymphedema after Surgery, Chemotherapy and Radiation, OR;

0.4:CI; 0.2-0.9 P Value= 0.002, 0.1 more likely to develop lymphedema after surgery and chemotherapy OR 0.0 CI:0.0-0.7 P Value = 0.034 and 0.1 more likely to develop lymphedema after surgery OR;0.1 CI 0.0-0.8 P Value =0.004. A borderline statistically significant results was also obtained from those on the combination of Surgery, Chemotherapy, Radiotherapy and Hormonal therapy OR;0.5; CI: 0.1-0.4 P Value = 0.065.

**Table 4.6 Relationship of Breast cancer treatments and development of lymphedema**

| Breast cancer treatments | Developed Lymphedema (%) | No Development of Lymphedema(%) | OR(CI) | P-VALUE |
|---|---|---|---|---|
| Surgery alone | 9 (4.7) | 183 (95.3) | 0.1(0.0-0.8) | 0.004 |
| Surgery & Chemotherapy | 17 (8.8) | 175 (91.2) | 0.1(0.0-0.7) | 0.034 |
| Chemotherapy alone | 17 (8.8) | 175 (91.2) | 0.1(0.0-0.9 | 0.007 |
| Surgery, Chemotherapy& Radiotherapy | 53 (27.6) | 139 (72.4) | 0.4(0.2-0.9 | 0.002 |
| Chemotherapy& Radiotherapy | 9 (4.7) | 183 (95.3) | 0.1(0.0-0.8) | 0.003 |
| Chemotherapy, Radiotherapy & hormonal | 9 (4.7) | 183 (95.3) | 0.1(0.0-0.7) | 0.042 |
| Surgery, Chemotherapy, Radiotherapy & hormonal | 61 (31.8) | 131 (68.2) | 0.5(0.1-1.4) | 0.065 |
| surgery, chemotherapy & hormonal therapy | 17 (8.9) | 175 (91.2) | 0.3(0.1-0.8) | 0.003 |

### 4.5.2 Time taken to develop Lymphedema

The time taken to development lymphedema symptoms after the diagnosis of breast cancer. The asymmetrical distributions showed some patients took several months to development lymphedema symptoms as shown by the top whisker. The median time taken to development of lymphedema symptoms from breast cancer diagnosis was 12.5 (IQR=8.1, 22.8).

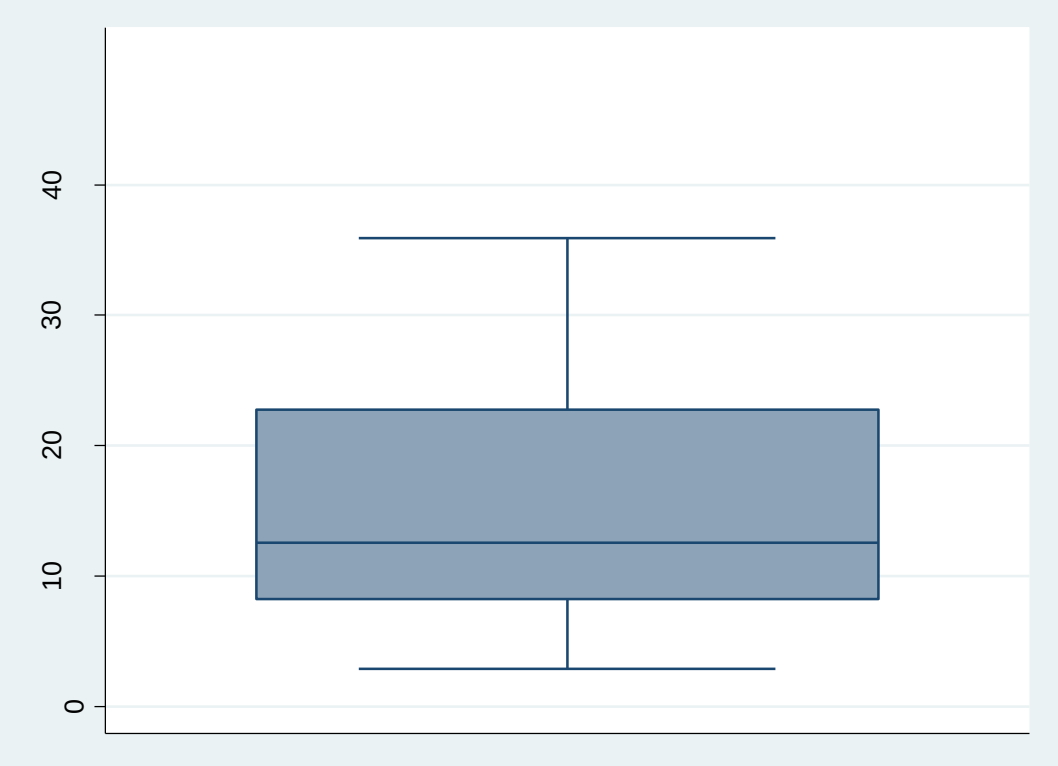


**Figure 4.1 Time taken to develop Lymphedema (Patients)**

### 4.5.3 Treatment Strategies for Lymphedema

The results show different types of treatment strategies used for treating lymphedema as reported by patients. Table 4.7 shows the patients used more than one treatment strategies, the highest proportion used prescribed exercise (58.8%) and medical treatment (59.4%).

**Table 4.7 Lymphedema treatment strategies**

| Variable | Used strategy N(%) | Strategy not used N(%) |
|---|---|---|
| Self-massage | 96 (50.0) | 96 (50.0) |
| Lymphatic drainage | 52 (27.3) | 140 (72.7) |
| Laser therapy | 17 (8.8) | 175 (91.1) |
| Compression bandaging | 87 (45.3) | 104 (54.2) |
| Prescribed exercises | 113 (58.8) | 78 (40.6) |
| Surgery | 30 (15.6) | 162 (84.4) |
| Medication | 114 (59.4) | 78 (40.6) |

#### 4.5.3.1 The propotion of patients who reported symptom and the treatment used

The Table 4.8 shows the propotion of patients who repoted symptoms and the percentage who used the type of treatment. The treatments the highest proportion of patients reported using was medical treatment, excesices, compresion bandaging and self massage.

**Table 4.8 The proportion of patients who experienced each symptom, the treatment used and how the treatment helped in improving each symptom**

| **Treatment Strategies** / **Symptoms** | Compression Garments | Self-massage | Manual Lymphatic Drainage | Exercises | Surgery | Medical Treatment |
|---|---|---|---|---|---|---|
| Tightness | N = 87 (100.0%)<br>n = 52 (60.0%) | N = 96 (100.0%)<br>n = 62 (64.6%) | N = 52 (100.0%)<br>n = 26 (50.0%) | N = 113 (100.0%)<br>n = 61 (54.0%) | N = 17 (100%)<br>n = 8 (47.0%) | N = 113 (100.0%)<br>n = 69 (61.1%) |
| Heaviness | N = 87 (100.0%)<br>n = 44 (50.6%) | N = 96 (100.0%)<br>n = 53 (55.2%) | N = 52 (100.0%)<br>n = 26 (50.0%) | N = 113 (100.0%)<br>n = 70 (61.9%) | N = 17 (100%)<br>n = 8 (47.0%) | N = 113(100.0%)<br>n = 53 (46.9%) |
| Tenderness | N = 87 (100.0%)<br>n = 52 (60.0%) | N = 96 (100%)<br>n = 53 (55.2%) | N = 52 (100.0%)<br>n = 26 (50.0%) | N = 113 (100.0%)<br>n = 61 (54.0%) | N = 17 (100.0%)<br>n = 17 (100.0%) | N = 113 (100.0%)<br>n = 53 (46.9%) |
| Pain | N = 87 (100.0%)<br>n = 52 (60.0%) | N = 96 (100%)<br>n = 62 (64.6%) | N = 52 (100.0%)<br>n = 9 (17.3%) | N = 113 (100.0%)<br>n = 60 (53.1%) | N = 17 (100.0%)<br>n = 8 (47.0%) | N = 113 (100.0%)<br>n = 61 (54.0%) |
| Weakness | N = 87 (100.0%)<br>n = 52 (60.0%) | N = 96 (100.0%)<br>n = 44 (45.8%) | N = 52 (100.0%)<br>n = 35 (67.3%) | N = 113 (100.0%)<br>n = 60 (53.1%) | N = 17 (100.0%)<br>n = 8 (47.0%) | N = 113 (100.0%)<br>n = 53 (46.9%) |
| Stiffness | N = 87 (100.0%)<br>n = 52 (60.0%) | N = 96 (100.0%)<br>n = 61 (63.5%) | N = 52 (100.0%)<br>n = 26 (50.0%) | N = 113 (100.0%)<br>n = 70 (61.9%) | N = 17 (100.0%)<br>n = 8 (47.0%) | N = 113 (100.0%)<br>n = 61 (54.0%) |
| Numbness | N = 87 (100.0%)<br>n = 35 (40.2%) | N = 96 (100.0%)<br>n = 44 (45.8%) | N = 52 (100.0%)<br>n = 26 (50.0%) | N = 113 (100.0%)<br>n = 44 (38.9%) | N = 17 (100.0%)<br>n = 0 | N = 113 (100.0%)<br>n = 35 (31.0%) |
| Swelling | N = 87 (100.0%)<br>n = 43 (49.4%) | N = 96 (100.0%)<br>n = 70 (72.9%) | N = 52 (100.0%)<br>n = 26 (50.0%) | N = 113 (100.0%)<br>n = 60 (53.1%) | N = 17 (100.0%)<br>n = 8 (50.0%) | N = 113 (100.0%)<br>n = 61 (54.0%) |
| Range of movement | N = 87 (100.0%)<br>n = 61 (70.1%) | N = 96 (100.0%)<br>n = 61 (63.5%) | N = 52 (100.0%)<br>n = 44 (84.6%) | N = 113 (100.0%)<br>n = 70 (61.9%) | N = 17 (100.0%)<br>n = 17 (100.0%) | N = 113 (100.0%)<br>n = 69 (61.1%) |

**Note:**

**N** represents the Total number of patients who used different treatment strategies and reported different symptoms.

**n** represent patients who used different treatment strategies and reported improvement in lymphedema symptoms.

On exploring the strategies used in the management of lymphedema findings from focus group discussion results showed that mostly used lymphedema treatment strategies were physical excises and compression bandaging

*"...patients do light exercises and increase with time and apart from exercises patients also use stockings..." (Care Provider, FGD1).*

The results- from focus group discussion also show that most healthcare providers had a good understanding of the strategies used in the management of lymphedema and used them to provide care to the patients but suggested for more training opportunities to update their knowledge.

*"....When we get patients, we advise them to do exercises, we advised them to hung their hands while sitting in this position their pain is lessened. using stockings is another method. surgical interventions can also be used though we don't have updates on the latest management of lymphedema...."(*FGD2 and *4).*

Lastly there was evidence of some confusion about the prevention of lymphedema some saying removing lymph nodes improve lymphedema, which instead worsens.

*"....Lymphedema can't be cured but the swelling can be prevented from getting worse. can be prevented by maintaining normal weight, screening before the patient develop symptoms, and if the patient has breast cancer depending on the stage if all glands are removed then lymphedema is prevented...." (*FGD1, 3, 5).

**4.6 The outcome of lymphedema treatment strategy among breast cancer patients**

The results show the number of patients who used each treatment strategy and the outcome. The table 4.9 show the results of the proportion of patients who used different strategies for lymphedema treatment and either reported improvement or no improvement. There was significant difference in outcome to treatment strategies. When using medical treatment patients were 3.3 times more likely to report improvement(OR:3.3; 95%CI: 1.6-6.5: P =0.005, physical exercise 1.6 times more

likely to report improvement (OR:1.6; 95% CI: 1.1-3.2: P =0.032), lymphatic drainage 4.3 times more likely to report improvement (OR: 4.3; 95%CI: 1.9-5.2: P=0.021).other treatments did not yield statistically significant results.

**Table 4.9 Bivariate analysis on the outcome of lymphedema treatment**

| Treatment used | Total n (%) | Lymphedema Symptoms improvement/ no improvement n (%) | | OR | 95% C.I | P. Value |
|---|---|---|---|---|---|---|
| Medication | 114(59.4) | Improvement | 88(77) | 3.3 | 1.6-6.9 | 0.005 |
| | | No. improvement | 26(23) | | | |
| Physical exercises | 113(58.8) | Improvement | 70(62) | 1.6 | 1.1-3.2 | 0.032 |
| | | No. improvement | 43(38) | | | |
| Compression bandaging | 87(45.3) | Improvement | 49(56) | 1.3 | 0.4-4.8 | 0.376 |
| | | No. improvement | 38(44) | | | |
| Lymphatic drainage | 52(27.3) | Improvement | 42(81) | 4.3 | 1.9-5.2 | 0.021 |
| | | No. improvement | 10(19) | | | |
| Self-massage | 96(50) | Improvement | 48(50) | 1.0 | - | - |
| | | No Improvement | 48(50) | | | |
| Surgery | 30(15.5) | Improvement | 11(37) | 0.59 | 0.2-7.6 | 0.490 |
| | | No. improvement | 19(63) | | | |

About the patient's treatment outcome findings from the focus group discussions revealed that health care providers were in agreement in FGD1 & FGD2 that their patients were lost for follow up as shown in the extract below.

"……*most of our patients , those we have seen at the clinic, it is difficult to actually objectively assess the compliance because most of them we just give them the information but we can't tell whether they are actually doing what you instructed them to do back in their homes, but we can only assess when they come and there is improvement in lymphedema, if not then we can conclude as clinicians that probably*

*the patient followed the instructed though subjectively we can say that either they are not keen on doing the excesses or they have tried and it is not working that is why the lymphedema progresses…." (FGD 1 and 2)."*

# CHAPTER FIVE

# DISCUSSION

## 5.1 Overview

This chapter presents the interpretation and discussion of the results of the effectiveness of clinical management strategies for lymphedema. The study sought to investigate healthcare providers competence which include knowledge and skills, examine strategies used in management of lymphedema and determine the patients treatment outcome.

## 5.2 Healthcare providers' competence in clinical management for lymphedema secondary to breast cancer treatment.

Health care providers competence entails knowledge and skills in management of lymphedema

### 5.2.1 Healthcare providers' knowledge in clinical management of lymphedema

A total of 192 Healthcare providers were selected from Kakamega, Kisumu, Bungoma, Bomet and Siaya Counties to participate in the study registering 100% response rate. Most participants were female, with a higher response observed among nurses .This is similar to a previous study by Michelini *et al.,*(2018) which reported that nurses are the majority and mostly female. The reason could be nursing has traditionally been a female dominated profession and comprises the largest component of the healthcare environment.

Knowledge was assessed by use of multiple-choice questions, findings show that, 26(13.5%) did not pass the knowledge test and out of the 166 (86.5%) . A study by Bayinje *et al.,* (2020) on healthcare providers knowledge reported failure rate of 60% out of 152 participants . In this study despite recording a low failure rate there was a

deficit of knowledge in important areas of practice such as skin care, stocking application, and diagnosis with over 50% getting wrong answers.

Those who got the correct answers in important areas (OR=2.717, P = 0.001)were less likely to get distinction than those who scored well in other questions (OR=2.249,P=0.003). The discrepancies among healthcare providers in this study is a clear indication that multidisciplinary approach reported in the literature was not practiced.

In this study the demographic characteristics revealed a higher response from nurses (65.6%) and the majority were diploma/ certificate holders, similar to the previous study which reported that nurses are the majority (Michelini *et al.,* 2018).

In this study the association between demographic variables and scores showed that professional qualification mostly influenced higher scores. Significant results were obtained from medical officers and clinical officers with the means of 76.7% and 69.4% 17.1 and 11.6 more likely to perform better than nurses( OR; 17.7 CI( 8.2-27.2 P Value =0.001 and OR;11.6 CI;5.1-8.2 P Value =0.001 ). This is similar to global open study that showed academic qualification, profession, and experience as a significant relationship with knowledge (Selber *et al.,* 2020). This is also similar to a study by Yormohamadi *et al.,*(2021). that reported Professional qualification as a factor that influenced health care provider's knowledge. Nurses and those in the other subgroup had the lowest scores with the mean score of 56.3% and 57.5 contrary to previous studies that reported that nurses are knowledgeable and have critical thinking skill to provide the best outcome (Keyiran *et al.,* 2017) and make a huge impact on the patient's quality of life (Michelini *et al.,* 2018).

In this study work experience also played a role because those above 51 years of age performed better than others (OR:6.3; 95% CI;1.2-30.0;P=0.026) similar to a study by Selber *et al.,* (2020) that reported work experience as one of the factors that influenced better performance. Self-reported knowledge had higher odds ration compared to the test results these could be due to subjects not being able to assess themselves correctly or may not be truthful, qualitative results show deficit of knowledge among healthcare providers by failure to clearly define lymphedema which must include what lymphedema is, the courses, risk factors and signs and symptoms. Qualitative data shows deficit of knowledge among healthcare providers by failure to clearly define lymphedema.

Example is the extract below

*"…. it's just a swelling in the legs or arms*"…(care provider k*).*This is contrary to reports by most healthcare providers that they were knowledgeable.

### 5.2.2 Healthcare provider's skills in clinical management of lymphedema

In a study by Ruwowicz *et al .,* (2016) states that Healthcare Providers with appropriate training depend on practical efficiencies and tests in order to accurately measure diagnose and manage lymphedema. The skills in the current study were assessed by direct observation as healthcare providers provided the care to the patients a better performance was observed in history taking and physical examination with Cronbach's alpha of 60 to 70% respectively. Vital information such as complication assessment, prevention intervention and follow-up appointments were missed out across all health facilities. These tallies to a study by Bayinge *et al.,* (2020) that reported lack of knowledge regarding assessment, examination, patient education and follow up appointments. This was consistent with a study by Mohammadi *et al.*, (2021) in Iran

which showed that educational needs of healthcare providers regarding care of patients were reported either as adequate or poor. These may be due to lack of commitment or due to shortage of staff and time allocated for each patient is limited. A previous study by Finnane *et al.,* (2015) affirms the current study that transferring skill for self-management to the patient through health education is very important is very important.

### 5.3 Effectiveness of Strategies used in clinical management of lymphedema secondary to breast cancer treatment in selected hospitals in western region

The patients who participated in the study who were all females, demographic characteristics showed most patients who developed lymphedema were aged between 43 and 60 years, the median age was 53.5 (IQR=43,60). Most of them were self-employed, 96 (50.0%), 113 (59.1%) were married and most of them were Christians, 157 (81.8%). The patients who developed lymphedema were on different treatment modalities such as surgery, chemotherapy, Radiotherapy, Hormonal therapy or combination of two or more treatments at different intervals. These findings were logical as other studies reported that lymphedema is caused by interruption of axilla lymphatic system by injury following breast cancer treatment such as surgery, chemotherapy and radiotherapy (Shaitelman *et al.,* 2015).

In this study time taken to development lymphedema symptoms ranged from months to years. The median time was 12.5 months(IQR 8.1-22.8). This is in agreement with a study by Foldi *et al.,* 2021 that rules out post-surgery lymphedema that develops after a few days. qualitative analysis showed most health care providers had a good understanding of treatment strategies and the patients used a range of strategies that was consistent with the previous study by Shaitelman *et al.,* (2015) which states that

treatment of lymphedema associated with breast cancer include self- massage, lymphatic drainage, prescribed exercises, compression bandaging, surgery, laser therapy, and medical treatment based on medical history, cancer and lymphedema status.

Similar patterns were reported internationally that treatment option for lymphedema treatment in breast cancer is selected for each patient based on medical history and cancer status (Krok-Schoen *et al.*,2015). In this study the results show that the patients used more than one Lymphedema treatment strategies, the highest proportion used prescribed exercise (58.8%) and medical treatment (59.4%).

This is consistent with a study by Shaitelman *et al.,*(2015). which stated that treatment of lymphedema included self-massage and prescribed exercises.

### 5.4 Outcome of Lymphedema Treatment

The outcome of lymphedema treatment was assessed by asking patients to indicate how much a treatment helped in improving lymphedema symptom, this conforms to similar previous study where treatment effectiveness was measured by asking patients to rank how a treatment helped improve symptoms (Singh *et al.,*2016).

Patients used different types of lymphedema treatment strategies such as medical treatment , lymphatic drainage, prescribed excesses, self- massage, lymphatic drainage and, compression bandaging. Most participants used prescribed physical exercises. These was consistent with a report by Wanchai *et al.*,(2016) that the greatest proportion of women with lymphedema used self-massage (89%) and exercise (62%). A cross all treatment strategies the highest proportion used physical exercise which was reported as most effective for improving symptoms. This is similar to the findings from the previous study by Hayes et al. (2015) on exploring the use of self-massage

and skin care that suggested improvement in symptoms and reduction in limb volume. Fewer patients reported improvement in symptoms following self-massage the reasons may be attributed to lack of supervision.

In this study the results showed treatment varied with a significant difference in response to each strategy by patients reporting improvement or no improvement and not all treatment strategies were beneficial. This is contrary to literature review that stated all single treatment were beneficial to all (Stralia *et al.*,2013). These results suggest that the combination of treatment may offer the greatest benefit to patients in terms of symptom improvement.

# CHAPTER SIX

# CONCLUSION AND RECOMMENDATIONS

## 6.1 Overview

This chapter represents the conclusion and recommendations guided by specific objectives, with attempts to answering the research questions.

## 6.2 Conclusions

### 6.2.1 Healthcare Providers' competence in clinical management of lymphedema secondary to breast cancer treatment

Health care provider`s competence include knowledge and skills in management of lymphedema.

#### 6.2.1.1 Health care providers' knowledge in clinical management of lymphedema

This research assessed healthcare providers competence in management of lymphedema, knowledge test healthcare providers' were `not knowledgeable because some participants failed to attain the pass mark while the majority ranged from low to average performance ranged from low to average. And focus group discussions revealed that some could not clearly define lymphedema.

#### 6.2.1.2 Healthcare providers' skills in clinical management of lymphedema

Skills demonstrated by health care providers showed better performance in history taking, physical examination, but critical information about patient education and follow up interventions were not practiced.

### 6.2.2 Strategies in clinical management of lymphedema secondary to breast cancer treatment in selected hospitals in western region

In this study lymphedema management strategies are effective when healthcare providers are knowledgeable, the patient's diagnosis is made early and the patients, when more than one strategy is used and patients are compliant to the treatment.

### 6.2.3 Outcome of lymphedema treatment among breast cancer patients

In this study there was a significant difference in response each treatment strategy by patients either reporting improvement or no improvement and not all single treatments were beneficial to all. The highest proportion of patients used medical treatment, physical exercise and compression bandages which were reported as most effective for improving symptoms. self-massage was also used by a large number but with poor response which may be attributed to lack of health education or not being supervised.

## 6.3 Recommendations

- On competence the study recommends that training opportunities on lymphedema management should be made available and accessible to healthcare provides to better understand lymphedema management. And since the literature in the study support practical efficiencies training then this provides evidence for establishing lymphedema management training programs to develop health care providers skill development.
- On strategies used in the management of lymphedema more treatment options should be implemented such as patient education, follow up and monitoring strategies to give our patients quality care.

- On the patient's outcome this study showed responses to treatment varied and not all strategies were beneficial. This result emphasizes the need for healthcare providers to consider, individual responses and combination of treatment to offer long term treatment effectiveness in terms of symptom management.

- Finally, further research is required to determine the exact burden of lymphedema in breast cancer patients.

## REFERENCES


American Cancer Society. Breast cancer facts and figures 2016. Atlanta: ACS; 2016.

Armer, J. M., & Whitman, M. (2002). The problem of lymphedema following breast cancer treatment: Prevalence, symptoms, and self-management. *Lymphology*, *35*(Suppl), 153-159.

Armer, J. M., Ballman, K. V., McCall, L., Ostby, P. L., Zagar, E., Kuerer, H. M., ... & Boughey, J. C. (2019). Factors associated with lymphedema in women with node-positive breast cancer treated with neoadjuvant chemotherapy and axillary dissection. *JAMA surgery*, *154*(9), 800-809.

Armer, J. M., Hulett, J. M., Stewart, B. R., & Wanchai, A. (2015). Perspectives of the breast cancer survivorship continuum: diagnosis through 30 months post-treatment. *Journal of Personalized Medicine*, *5*(2), 174-190.

Armer, J. M., Sun, Y., & Shigaki, C. L. (2017). Return to work among breast cancer survivors: a literature review. *Supportive Care in Cancer*, *25*(3), 709-718.

Armer, J. M., Wanchai, A., Stewart, B. R., & Lasinski, B. B. (2016). Breast cancer-related lymphedema: A literature review for clinical practice. *International Journal of Nursing Sciences*, *3*(2), 202-207.

Ayre, K., & Parker, C. (2019). Lymphedema after treatment of breast cancer: a comprehensive review. *Journal of Unexplored Medical Data*, *4*, 5.

Bayinje, U., Schure, J., Wony, R., Amuguni, H., & Pavey, G., "Survey on health professionals' knowledge and attitude on neglected tropical diseases" *international journal of vascular medicine* vol 14 no 10 (2020)article e008740.

British Lymphology Society. (2016). Consensus document on the management of cellulitis in lymphoedema. *Revised Guidance December 2016*.

Borman, Pınar, Ayşegül Yaman, Sina Yasrebi, and Oya Özdemir. "The importance of awareness and education in patients with breast cancer-related lymphedema." *Journal of Cancer Education* 32, no. 3 (2017): 629-633.

Cheville, A. L., McGarvey, C. L., Petrek, J. A., Russo, S. A., Taylor, M. E., & Thiadens, S. R. (2003, July). Lymphedema management. In *Seminars in radiation oncology* (Vol. 13, No. 3, pp. 290-301). WB Saunders.

Chubak J., Wagner, E. H., Ludman, E. J., Bowles, E. J. A., Penfold, R., Reid, R. J., R. M., ... & McCorkle, R. (2014). Nurse navigators in early cancer care: a randomized, controlled trial. *Journal of clinical oncology*, *32*(1), 12.

Cohen, S. R., Payne, D. K., & Tunkel, R. S. (2001). Lymphedema: strategies for management. *Cancer: Interdisciplinary International Journal of the American Cancer Society*, *92*(S4), 980-987.

Connell, F. C., Gordon, K., Brice, G., Keeley, V., Jeffery, S., Mortimer, P. S., ... & Ostergaard, P. (2013). The classification and diagnostic algorithm for primary lymphatic dysplasia: an update from 2010 to include molecular findings. *Clinical genetics*, *84*(4), 303-314.

Corner, J., Wagland, R., Glaser, A., & Richards, M. (2013). Qualitative analysis of patients' feedback from a PROMs survey of cancer patients in England. *BMJ open*, *3*(4), e002316.

Demographic, K. K. Health Survey (2014) https://dhsprogram. com/pubs/pdf/FR308. *FR308. pdf*.

Deng, J., Ridner, S. H., Bonner, C. M., & Sinclair, V. G. (2012). Voices from the shadows: living with lymphedema. *Cancer nursing*, *35*(1), E18.

Denlinger, C. S., Ligibel, J. A., Are, M., Baker, K. S., Demark-Wahnefried, W., Dizon, D., ... & Freedman-Cass, D. A. (2014). Survivorship: healthy lifestyles, version 2.2014. *Journal of the National Comprehensive Cancer Network*, *12*(9), 1222-1237.

Durarl LC., Tomadon A., Cabion FF., SilviaJ., Campos R.B., Bezerra R.,&Gozzo T.O.,(2019). Survival risk factor in women with breast cancer. The relationship of lymphedema.

Eyigor, S., Cinar, E., Caramat, I., & Unlu, B. K. (2015). Factors influencing response to lymphedema treatment in patients with breast cancer-related lymphedema. *Supportive Care in Cancer*, *23*(9), 2705-2710.

ISL, I. (2013). The diagnosis and treatment of peripheral lymphedema: 2013 Consensus Document of the International Society of Lymphology. *Lymphology*, *46*(1), 1-11.

Fialka-Moser, V., Korpan, M., Varela, E., Ward, A., Gutenbrunner, C., Casillas, J. M., ... & Christodoulou, N. (2013). The role of physical and rehabilitation medicine specialist in lymphoedema. *Ann Phys Rehabil Med*, *56*(5), 396-410.

Finnane, A., Janda, M., & Hayes, S. C. (2015). Review of the evidence of lymphedema treatment effect. *American journal of physical medicine & rehabilitation*, *94*(6), 483-498.

Foldi, E., Rabe, E., Gerlach, H., Jünger, M., Lulay, G., Miller, A., ... & Pannier, F. (2021). Medical compression therapy of the extremities with medical compression stockings (MCS), phlebological compression bandages (PCB), and medical adaptive compression systems (MAC). *Der Hautarzt*, 1-14.

Gillespie, E. F., Chen, V. E., Zakeri, K., Murphy, J. D., Yashar, C. M., Lu, S., & Einck, J. P. (2017). Pathologic response after neoadjuvant chemotherapy predicts locoregional control in patients with triple negative breast cancer. *Advances in Radiation Oncology*, *2*(2), 105-109.

Gillespie, T. C., Sayegh, H. E., Brunelle, C. L., Daniell, K. M., & Taghian, A. G. (2018). Breast cancer-related lymphedema: risk factors, precautionary measures, and treatments. *Gland surgery*, *7*(4), 379.

Hayes, S., DiSipio, T., Rye, S., & Newman, B. (2013). Incidence of unilateral arm lymphoedema after breast cancer: a systematic review and meta-analysis. *The lancet oncology*, *14*(6), 500-515.

Hayes, S., DiSipio, T., Rye, S., & Newman, B. (2016). Incidence of unilateral arm lymphoedema after breast cancer: a systematic review and meta-analysis. *Jclin Oncology* , *14*(6), 500-515

Heisig, S. R., Shedden-Mora, M. C., von Blanckenburg, P., Rief, W., Witzel, I., Albert, U. S., & Nestoriuc, Y. (2016). What do women with breast cancer expect from their treatment? Correlates of negative treatment expectations about endocrine therapy. *Psycho‐oncology*, *25*(12), 1485-1492.

Herrmann, J., Lerman, A., Sandhu, N. P., Villarraga, H. R., Mulvagh, S. L., & Kohli, M. (2014, September). Evaluation and management of patients with heart disease and cancer: cardio-oncology. In *Mayo Clinic Proceedings* (Vol. 89, No. 9, pp. 1287-1306). Elsevier.

Hossein, Y.,Amirhossein,R.,Masood, S.,Avmirabbas, S., &Seyed,F.M.A(2021) Health practionners knowledge of lymphedema. *International journal of vascular medicine*. Vol. Article ID 3806150, 11 pages.

Jacobs, M. A., Umbricht, C. B., Parekh, V. S., El Khouli, R. H., Cope, L., Macura, K. J., ... & Wolff, A. C. (2020). Integrated multiparametric radiomics and informatics system for characterizing breast tumor characteristics with the OncotypeDX gene assay. *Cancers*, *12*(10), 2772.

James, M. (2012). Cancer Compass. Living Well with Lymphedema. Retrieved from http://www.cancercompass.com/cancer-news/article/living-well-withlymphedema

Katzel, E. B., Nayar, H. S., Davenport, M. P., Bossert, R. P., Rubin, J. P., & Gusenoff, J. A. (2014). The influence of preexisting lower extremity edema and venous stasis disease on body contouring outcomes. *Annals of Plastic Surgery*, *73*(4), 365-370.

Kantelhard,E. J.,Zerche P.,Mathes, A.,Troch, P., Addissie, A.,Aynalem, A.,Wondemagegnehu, T.(2014).Breast cancer survival in Etiopia: Acohort study of 1070 women int.J.Cancer,135(3) 702-709.

Kayiran, O., De La Cruz, C., Tane, K., & Soran, A. (2017). Lymphedema: From diagnosis to treatment. *Turkish Journal of Surgery*, *33*(2), 51.

Keast, D. H., & Towers, A. (2017). The rising prevalence of lymphedema in Canada: A continuing dialogue. *Pathw. Can. Lymphedema Mag*, 5-8.

Krok-Schoen, J. L., Oliveri, J. M., Kurta, M. L., & Paskett, E. D. (2015). Breast cancer-related lymphedema: risk factors, prevention, diagnosis and treatment. *Breast Cancer Management*, *4*(1), 41-51.

Marchina P., D'arpa S., and Magro S.(2021). Integrated treatment of breast cancer related lymphedema.; a descriptive review of the state-of-the-art anticancer Res 41(7) 3233-3246

Mathers, C., Ferlay, J., Soerjomataram, I., Dikshit, R., Eser, S., Rebelo, M., ... & Bray, F. (2015). Cancer incidence and mortality worldwide: sources, methods and major patterns in GLOBOCAN 2012. *International journal of cancer*, *136*(5), E359-E386.

MathewsB., Miles Michael Huberman, & Saldama, J. (2014). Qualitative data SAGE analysis Sage: An expanded source boo pg. 379.

McCaulley, L., & Smith, J. (2014). Diagnosis and Treatment of Lymphedema in Patients With Breast Cancer. *Clinical Journal of Oncology Nursing*, *18*(5).

Mehrara, B. J., Kataru, R. P., Baik, J. E., Park, H. J., Wiser, I., Rehal, S., & Shin, J. Y. (2019). Regulation of immune function by the lymphatic system in lymphedema. *Frontiers in immunology*, *10*, 470.

Mergan, F., Garofalo, G., Tecco, L., Van Rysselberge, M., Van Bogaert, P., & Cassart, M. (2016). Unusual association of brain hemorrhage and digestive tract occlusion: about two prenatal cases. *Clinical case reports*, *4*(12), 1168.

Michelini, S., Paolacci, S., Manara, E., Eretta, C., Mattassi, R., Lee, B. B., & Bertelli, M. (2018). Genetic tests in lymphatic vascular malformations and lymphedema. *Journal of Medical Genetics*, *55*(4), 222-232.

Milambo, J. P. M., Tshilombo, V. K., Ndayisaba, L., & Jacques, T. (2018). Current Level of Evidence on Late Complications of Breast-Cancer Management in Democratic Republic of the Congo: Review of literature. *J Oncol Res Ther: JONT-144. DOI*, *10*.

Molica, F., Meens, M. J., Morel, S., & Kwak, B. R. (2014). Mutations in cardiovascular connexin genes. *Biology of the Cell*, *106*(9), 269-293.

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook*. sage.

Mugenda, O., & Mugenda, A. (2003). Research methods: Quantitative and Qualitative methods. *Revised in Nairobi*, *56*(12), 23-34.

Olasehide O., Alatise., & Omisore A., (2021) Contemporary treatment of breast cancer related lymphedema : A system review Asian Pac J cancer Prev APJCP 17 (11) 4875-4883.

Palya, Z., Hampel, K., & Kiss, R. M. (2018). Lymphedema treatment's effect of gait parameters. *Materials Today: Proceedings*, *5*(13), 26526-26531.

Papadopoulou, M. C., Tsiouri, I., Salta-Stankova, R., Drakou, A., Rousas, N., Roussaki-Schulze, A. V., & Giannoukas, A. D. (2012). Multidisciplinary lymphedema treatment program. *The International Journal of Lower Extremity Wounds*, *11*(1), 20-27.

Parisot, J. P., Thorne, H., Fellowes, A., Doig, K., Lucas, M., McNeil, J. J., ... & Thomas, D. M. (2015). "Cancer 2015": a prospective, population-based cancer cohort—phase 1: feasibility of genomics-guided precision medicine in the clinic. *Journal of personalized medicine*, *5*(4), 354-369.

Position Statement of the National Lymphedema Network. The diagnosis and treatment of lymphedema, NLN Medical Advisory Committee 2011. http://www.lymphnet.org/pdfDocs/ nlntreatment.pdf. Accessed 6 June 2022.

Park, S. O., Bae, J. S., Yoo, R. E., Choi, S. H., Chang, H., Suh, M., & Cheon, G. J. (2018). Evaluation of lymphedema in upper extremities by MR lymphangiography: Comparison with lymphoscintigraphy. *Magnetic Resonance Imaging*, *49*, 63-70.

Rebegea, L., Firescu, D., Dumitru, M., & Anghel, R. (2015). The incidence and risk factors for occurrence of arm lymphedema after treatment of breast cancer. *Chirurgia (Bucur)*, *110*(1), 33-37.

Ridner, S. H., Sinclair, V., Deng, J., Bonner, C. M., Kidd, N., & Dietrich, M. S. (2012). Breast Cancer Survivors With Lymphedema. *Clinical journal of oncology nursing*, *16*(6).

Riogi, E. K. (2015). Effect of a navigation program on patient return after an abnormal clinical breast cancer screening examination finding at Aga khan University Hospital, Nairobi.

Runowicz, C. D., Leach, C. R., Henry, N. L., Henry, K. S., Mackey, H. T., Cowens-Alvarado, R. L., ... & Ganz, P. A. (2016). American cancer society/American society of clinical oncology breast cancer survivorship care guideline. *CA: a cancer journal for clinicians*, *66*(1), 43-73.

Safwat, S., Hathout, R. M., Ishak, R. A., & Mortada, N. D. (2017). Augmented simvastatin cytotoxicity using optimized lipid nanocapsules: a potential for breast cancer treatment. *Journal of Liposome Research*, *27*(1), 1-10.

Sawers, L., & Stillwaggon, E. (2020). Economic costs and benefits of community-based lymphedema-management programs for lymphatic filariasis in India. *The American journal of tropical medicine and hygiene*, *103*(1), 295.

Shaitelman, Simona F., Kate D. Cromwell, John C. Rasmussen, Nicole L. Stout, Jane M. Armer, Bonnie B. Lasinski, and Janice N. Cormier. "Recent progress in the treatment and prevention of cancer-related lymphedema." *CA: a cancer journal for clinicians* 65, no. 1 (2015): 55-81.

Schaverien, M.V., Baumann, D.P., Selber, J, C.(2020). Building a multidisplinary comprehensive academic lymphedema program plastic and reconstructive surgery Global open, Volume 8, no 3 p, e2670-2020

Sung, H., Ferlay .J., Siegel .RL., Laversanne .M., Soerjomataram .I., Jemal .A. (2020). Globocan estimate of incidence and mortality worldwide for 36 cancers in 185 counties CA J Clin.2021 may.

Sekyere M,& Owusu (2018). incidence and risk factors of arm lymphedema following breast cancer treatment. *American society of clinical oncology journal.*

Shigaki, H., Baba, Y., Watanabe, M., Murata, A., Iwagami, S., Miyake, K., ... & Baba, H. (2013). LINE-1 hypomethylation in gastric cancer, detected by bisulfite pyrosequencing, is associated with poor prognosis. *Gastric Cancer*, *16*(4), 480-487.

Sierla, R., Lee, T. S. M., Black, D., & Kilbreath, S. L. (2013). Lymphedema Following Breast Cancer: Regions Affected, Severity of Symptoms, and Benefits of Treatment from the Patients' Perspective. *Clinical Journal of Oncology Nursing*, *17*(3).

Singer, M. (2009). Lymphedema in breast cancer: dilemmas and challenges. Clinical Journal of Oncology Nursing, 13(3), 350-352. Doi:10.1188/09.CJON.350-352.

Singh, B., Disipio, T., Peake, J., & Hayes, S. C. (2016). Systematic review and meta-analysis of the effects of exercise for those with cancer-related lymphedema. *Archives of physical medicine and rehabilitation*, *97*(2), 302-315.

Stewart, D. W., & Shamdasani, P. N. (2014). *Focus groups: Theory and practice* (Vol. 20). Sage publications.

Suehiro, K., Honda, S., Kakutani, H., Morikage, N., Murakami, M., Yamashita, O., ... & Hamano, K. (2014). A novel arm sleeve for upper extremity lymphedema: a pilot study. *Annals of vascular diseases*, oa-14.

Tann& Wilson (2019).Clinical outcome after physical therapy treatment for secondary lympedemic after breast cancer curious :11-15 e4779 published :May 30 dol 10.7759

Todd, M. (2015). Compression hosiery choices for managing chronic oedema. *Br J Community Nurs*, *20*(7), 318-320.

Torre, L. A., Bray, F., Siegel, R. L., Ferlay, J., Lortet-Tieulent, J., & Jemal, A. (2015). Global cancer statistics, 2012. *CA: a cancer journal for clinicians*, *65*(2), 87-108.

Wamalwa, A. O., Nangole, F. W., & Khainga, S. O. (2019). Lymph node transplant in Kenya: a case series of 20 patients. *South African Journal of Surgery*, *57*(1), 54-54.

Wanchai, A., Armer,J M., Stewart, B.R., Lasinsik B.B. Breast cancer related lymphedema; A Litereture review for clinical practice,International journal of nursing sciences 2016:3:202-207.

## APPENDICES

### APPENDIX I: Consent Form for Participant

**Study Topic:** *CLINICAL MANAGEMENT STRATEGIES FOR LYMPHEDEMA SECONDARY TO BREAST CANCER TREATMENT IN SELECTED HOSPITALS IN WESTERN REGION OF KENYA*

If you consent to participate in the study please sign below:

I hereby consent to participate in this study. I have been informed of the nature of the study being undertaken and potential risks explained to me. I also understand that my participation in this study is voluntary and decision to participate or not participate will not affect my status at this facility in any way whatsoever. I may also choose to discontinue my involvement in the study at any stage without any explanation or consequences. I have also been reassured that my personal details and the information that I will relay will be kept confidential. I confirm that all my concerns about my participation in the study have been adequately addressed by the investigator/research assistant and they have asked me questions to ascertain my comprehension of the information provided.

Participants Signature (or thumb print) ……Date……

I confirm that I have clearly explained to the participant the nature of the study and the contents of this consent form in detail and the participant has decided to participate voluntarily without any coercion or undue pressure.

Investigators signature ……..Date……..

For any Clarification, please contact

**ROSEMARY LUSIKE WEPUKHULU PHONE:** ***0725 290 365***

**APPENDIX II: Self-Report Questionnaire for Health Care Provider On Lymphedema**

Please indicate the name of the health facility----------

Please place a tick along the appropriate response to each statement.

**SECION A: Demographic Data**

1. What is your gender?

1)Male [ ]

2) Female [ ]

2. Please specify your age bracket?

1) Below 24 Years [ ] 2)25 - 30 Years [ ]

3) 31 - 34 years [ ] 4) 35 - 40 years [ ]

5) 41 - 44 years [ ] 6) 45 - 50 years [ ]

7) Over- 51 years [ ]

3 What is your professional background?

1) Nurse []
2) Clinical officer [ ]
3) Medical officer [ ]
4) Oncologist [ ]
5) Others specify……

3. What is your highest level of education held? (Tick as applicable)

1) Diploma/certificate [ ]
2) Bachelors' degree [ ]
3) Masters [ ]
4) Doctorate [ ]

**SECTION B**

Please specify to what extent you agree with the following statements regarding lymphedema, applying the Likert scale with responses ranging from strongly agree , agree , disagree and strongly disagree on the scale of 4,3,2.1 Please tick next to the appropriate column in the table below;

**4= Strongly Agree (SA) 3= Agree (A) 2= Disagree (D) 1= Strongly Disagree (SD)**

| Serial No. | ITEM | SA 4 | A 3 | D 2 | SD 1 |
|---|---|---|---|---|---|
| 1 | I can describe the etiology of lymphedema | | | | |
| 2<br>3 | I can describe secondary lymphedema<br>I can describe the possible risk factors of secondary lymphedema | | | | |
| 4 | I can describe the stages of secondary lymphedema | | | | |
| 5 | I can describe the clinical manifestation of secondary lymphedema | | | | |
| 6 | I can identify the needs of the patient with lymphedema secondary to breast cancer | | | | |
| 7 | I can describe the treatment plan for lymphedema | | | | |
| 8<br>9 | I can instruct a patient with lymphedema on self-care management<br>I can educate the patient with breast cancer on how to prevent lymphedema | | | | |
| 10 | I can identify long time complications associated with lymphedema | | | | |

**SECTION C: Multiple choice questions**

Q1. Why is skin care important for people with lymphedema?

A, tissues saturated with protein rich fluid are breeding ground for pathogens

B, patients are susceptible to skin and nail infections

C, local immune defense is law due to swelling and increased diffusion difference

D, skin becomes thickened and scaly and has higher risk for cracks and fissures

Q 2 In lymphedema stoking class A pressure is

A, 20____30 mm/hg

B, 30____40 mm/hg

C, 40____50 mm/hg

D, 50____60 mm/hg

Q3 a 60 year woman with locally advanced cancer of the left breast presented with resent onset of lymphedema on her left arm, she is not a candidate for radical resection and due to her pulmonary comorbidities , she is unable to tolerate radiotherapy , on examinations, she has a very swollen left arm ,elbow and wrist associated with ischemic changes in the finger of the left hand , there is no radial pulse and Doppler ultra sound scan shows no thrombus in any of the veins but reduced flow within her brachial arteries. What is the most appropriate initial management of her lymphedema?

A, multilayer lymphedema bandaging

B, manual lymphatic drainage

C, compression sleeve

D, surgical debunking

Q4, A positive stemmers sign test is a diagnosis of

A, Deep venous thrombosis

B, Lymphedema

C, superficial venous thrombosis

D, factitious lymphedema

Q5. A sentinel node is the first lymph node that

A, contains mature lymphocytes

B, produce an antibody in an immune reaction

C, to encounter an antigen

D, receives lymph drainage from the body area suspected of cancer

Q6 Patients who do not have symptoms within two years are no longer at risk of developing lymphedema

A, True

B, False

Q7, Early detection and intervention is the best way to reduce and manage lymphedema

A, False

B True

Q8, which statement is true about lymphedema?

A, a dense collection of all five leukocyte types

B, may reach the size of a golf ball

C, it is the abnormal collection of blood in the interstitium

D, it is the abnormal buildup of fluid in the soft tissue due to lymph blockage

Q9, Milroy's disease is

A, edema due to filariasis

B, post cellulitis lymphedema

C, congenital lymphedema

D, lymphedema following surgery

10, Treatment effectiveness is measured by how much a treatment has helped improve a certain symptom

A, False

B, True

**APPENDIX III: Skill Observation Check List for Healthcare Providers**
**APPENDIX IV: Lymphedema Clinical Assessment Checklist**

| Serial no | Parameters to be checked | Performed | Not performed | Comments |
|---|---|---|---|---|
| 1. History taking | Chief complains<br>-Increase in arm circumference<br>- Difficulty fitting in clothing<br>Med/surgical history<br>Hx of lymphedema and treatment type | | | |
| 2. Physical examination | Systemic examination<br>-Extent, location and Duration of edema<br>Symptoms assessment<br>-mild, moderate, severe<br>Vital sighs<br>Weight/height/BMI<br>Bp/RR/spo2<br>Pulse , temperature | | | |
| 3.Investigations | Limb volume<br>MRI<br>CT Scan<br>-Identify the needs of the patient with lymphedema | | | |
| 4. Physical activity | - current level of physical activity and any exercise program | | | |
| 5. Patient education | - On modifiable risk factors<br>- Signs and symptoms<br>.-Self-management | | | |

**APPENDIX V : Lymphedema Patient's Questionnaire**

Please place a tick along the appropriate response to each statement.

**SECION A: Demographic Data**

1. Age……..
2. Gender

   1) Female 2) Male
3. Occupation

   1) employed 2) self-employed 3) retired 4) others specify

4. Marital status

   1) Single 2) married 3) Widowed

5. Religion

   1) Christian 2) Muslim

   2) When were you diagnosed with breast cancer?

   ……./……./……..

   3) What treatment for breast cancer have you used ?

   1) surgery a) yes ( ) b) no ( )

   2) chemotherapy yes ( ) no ( )

   3) radiotherapy yes ( ) no ( )

   4) hormonal therapy yes ( ) no ( )

   5) others specify……

   4) When were you diagnosed with lymphedema?

   /……/……./……..

The following questions relates specifically to treatments you may have used for lymphedema

5) What type of treatment have you used for lymphedema?

1) self-massage yes( ) no ( )

2) lymphatic drainage yes( ) no ( )

3 ) laser therapy yes ( ) no( )

4) compression bandaging yes ( ) no( )

5) prescribed exercises yes ( ) no( )

6) surgery yes ( ) no( )

7) medical treatment yes ( ) no( )

8) if none of the above specify…….

**Treatment effectiveness**

10, How did the above treatment help you in improving the following symptoms? Mark the not applicable" box for the symptom not experienced

| | Very little | Little | Moderate | Very much | Not Applicable |
|---|---|---|---|---|---|
| Swelling | | | | | |
| Heaviness | | | | | |
| Tightness | | | | | |
| Pain | | | | | |
| Tenderness | | | | | |
| Stiffness | | | | | |
| Weakness | | | | | |
| Numbness | | | | | |
| Range of movement | | | | | |

**APPENDIX VI : Focus Group Discussion Guide**

Welcome and thank you for volunteering to take part in this focused group discussion, I realize you are busy but I appreciate your time. this group discussion is about the factors influencing the management of lymphedema.

The group discussion would take not more than two hours, I may tape the discussion to facilitate its recollection. Despite being taped, I would like to assure you that this discussion will be anonymous, the tapes will be safely locked until they are transcribed word to word then they will be destroyed the transcribed notes will not link any information to specific individual statements there for try to answer and comment as accurately as possible.

I and other group participants would appreciate if you would refrain from discussing the comments of others outside this group. Most importantly there are rules governing this discussion that is one person speaks at a time, there is no right or wrong answer, you do not have to participate in a particular order, you do not have to agree with other people in the group and if you have something to say please do so because it is important that I obtain the view of each of you

**Questions for focus group discussion of healthcare providers**

1. In your experience as healthcare providers, you must have come across breast cancer patients with lymphedema, in your own words let us know what lymphedema is?
2. What are risk factors for developing breast cancer related lymphedema?
3. What should patients do if they have lymphedema?
4. How can we reduce the risk of lymphedema?
5. What is the most commonly used treatment for lymphedema?
6. Are patients compliant?
7. How can we prevent lymphedema?

## APPENDIX VII: Letter from Directorate of Post Graduate Studies

**MASINDE MULIRO UNIVERSITY OF SCIENCE AND TECHNOLOGY (MMUST)**

Tel: 056-30870
Fax: 056-30153
E-mail: directordps@mmust.ac.ke
Website: www.mmust.ac.ke

P.O Box 190
Kakamega – 50100
Kenya

**Directorate of Postgraduate Studies**

**Ref:** MMU/COR: 509099

14th April, 2021

Rosemary Lusike Wepukhulu,
HNR/G/07/2016,
P.O. Box 190-50100,
**KAKAMEGA.**

Dear Ms. Wepukhulu,

**RE: APPROVAL OF PROPOSAL**

I am pleased to inform you that the Directorate of Postgraduate Studies has considered and approved your Masters Proposal entitled: ***"Clinical Management of Lymphedema Secondary to Breast Cancer Treatment by Healthcare Providers in Selected Hospitals in Western Region Kenya"*** and appointed the following as supervisors:

1. Prof. Lt. Col (Rtd) John M. Okoth - SONMAPS, MMUST
2. Dr. Damaris Ochanda - SONMAPS, MMUST

You are required to submit through your supervisor(s) progress reports every three months to the Director of Postgraduate Studies. Such reports should be copied to the following: Chairman, School of Nursing & Midwifery Graduate Studies Committee and Chairman, Department of Nursing Research, Education and Management and Graduate Studies Committee. Kindly adhere to research ethics consideration in conducting research.

It is the policy and regulations of the University that you observe a deadline of two years from the date of registration to complete your master's thesis. Do not hesitate to consult this office in case of any problem encountered in the course of your work.

We wish you the best in your research and hope the study will make original contribution to knowledge.

Yours Sincerely,

**Dr. Consolata Ngala**
**DEPUTY DIRECTOR, DIRECTORATE OF POSTGRADUATE STUDIES**

## APPENDIX VIII: Letter from IERC

MASINDE MULIRO UNIVERSITY OF SCIENCE AND TECHNOLOGY
P. O. Box 190-50100
Kakamega, Kenya
Tel: 056-31375
Fax: 056-30153
E-mail: ierc@mmust.ac.ke
Website: www.mmust.ac.ke
Institutional Ethics Review Committee (IERC)

**Ref:** MMU/COR: 403012 Vol 3 (01)

**Date:** 08th June, 2021

Rosemary Lusike
Masinde Muliro University of Science and Technology,
P.O. Box 190-50100,
Kakamega.

Dear Ms Lusike

**RE: Clinical Management of Lymphedema Secondary to Breast Cancer Treatment by Healthcare Providers in Selected Hospitals in Western Region Kenya. - MMUST/IERC/196/2021**

Thank you for submitting your proposal entitled as above for initial review. This is to inform you that the committee conducted the initial review and approved (with no further revisions) the above Referenced application for one year.
This approval is valid from **08th June, 2021** through to **08th June, 2022**. Please note that authorization to conduct this study will automatically expire on by **08th June, 2022.** If you plan to continue with data collection or analysis beyond this date please submit an application for continuing approval to the MMUST IERC by **08th June, 2022.**

Approval for continuation of the study will be subject to submission and review of an annual report that must reach the MMUST IERC Secretariat by **08th June, 2022.** You are required to submit any amendments to this protocol and any other information pertinent to human participation in this study to MMUST IERC prior to implementation.

Please note that any unanticipated problems or adverse effects/event resulting from the conduct of this study must be reported to MMUST IERC. Also note that you are required to seek for research permit from NACOSTI prior to the initiation of the study.

Yours faithfully,

Dr. Gordon Nguka (PhD)
**Chairman, Institutional Ethics Review Committee**

Copy to:
- The Secretary, National Bio-Ethics Committee
- Vice Chancellor
- DVC (PR&I)

## APPENDIX IX: Approval Letter from NACOSTI

REPUBLIC OF KENYA

NATIONAL COMMISSION FOR SCIENCE,TECHNOLOGY & INNOVATION

Ref No: **155622**

Date of Issue: **17/June/2021**

**RESEARCH LICENSE**

**This is to Certify that Ms.. Rosemary Lusike Wepukhulu of Masinde Muliro University of Science and Technology, has been licensed to conduct research in Bomet, Bungoma, Kakamega, Kisumu, Siaya on the topic: CLINICAL MANAGEMENT OF LYMPHEDEMA SECONDARY TO BREAST CANCER TREATMENT BY HEALTHCARE PROVIDERS IN SELECTED HOSPITALS IN WESTERN REGION KENYA for the period ending : 17/June/2022.**

License No: **NACOSTI/P/21/11282**

**155622**

Applicant Identification Number

Director General
NATIONAL COMMISSION FOR SCIENCE,TECHNOLOGY & INNOVATION

Verification QR Code

NOTE: This is a computer generated License. To verify the authenticity of this document, Scan the QR Code using QR scanner application.

## APPENDIX X :Authorization Letter from Kakamega County

REPUBLIC OF KENYA
COUNTY GOVERNMENT OF KAKAMEGA

OFFICE OF THE GOVERNOR
COUNTY SECRETARY AND HEAD OF PUBLIC SERVICE

Telephone: 056-31850/31852/31853
Website:www.kakamega.go.ke
E-mail:countysecretary@kakamega.go.ke

When replying please Quote

REF NO.CGK/OCS/GEN CRR/06(11)

County Government of Kakamega
P.O. Box 36-50100
KAKAMEGA

Date: 25th June, 2021

**Ms. Rosemary Lusike Wepukhulu**
**P.O Box 574-50300**
**Maragoli**

**RE: AUTHORITY TO COLLECT RESEARCH DATA**

The above subject matter refers,

This is to inform you that you have been granted permission to collect data on " *Clinical Management of Lymphedema Secondary to Breast Cancer Treatment by Healthcare Providers in Selected Hospitals in Western Region of Kenya*" for your Masters Degree of Science in Advanced Nursing Practice ( Oncology/ Palliative Care) at Masinde Muliro University of Science and Technology.

You are therefore required to adhere to Ethical standards and the County Government regulations on confidentiality.

Thank you

COUNTY SECRETARY
KAKAMEGA COUNTY
P.O. Box 36-50100
KAKAMEGA

**Jacinta Aluoch Odhiambo (Mrs.)**
**County Secretary and Head of Public Service**

**Copy to: H.E the Governor**

**I hereby commit to share the findings with the County Government of Kakamega through the undersigned.**

**Sign:** .....**Date:** 25.6.2021....

**APPENDIX XI: Authorization Letter from County Director of Education**

REPUBLIC OF KENYA

MINISTRY OF EDUCATION
STATE DEPARTMENT OF EARLY LEA3RING AND BASIC EDUCA4TION

Telephone: 056 -30411
Fax: 056 – 31307
E-mail: rceducation2016@gmail.com
When replying please quote our Ref.

County Director of Education
Kakamega County
P. O. BOX 137 - 50100
KAKAMEGA

**REF: KAKA/C/GA/29/17/VOL.V/120** **23rd June, 2021**

Ms. Rosemary Lusike Wepukhulu
Masinde Muliro University
Of Science & Technology
**KAKAMEGA**

**RE: RESEARCH AUTHORIZATION**

The above has been granted permission by National Council for Science & Technology vide letter Ref. NACOSTI/P/21/11282 dated 17th June,2021 to carry out research on "**Clinical Management of Lymphedema Secondary to Breast Cancer Treatment by Healthcare Providers in Kakamega County**" for a period ending 17th June, 2022.

Please accord him any necessary assistance he may require.

FOR
COUNTY DIRECTOR OF EDUCATION
KAKAMEGA COUNTY

DICKSON O. OGONYA
COUNTY DIRECTOR OF EDUCATION
KAKAMEGA COUNTY

CC
The Regional Director of Education
WESTERN REGION

**APPENDIX XII: Letter from Interior and Coordination of National Government**

# REPUBLIC OF KENYA

## MINISTRY OF INTERIOR AND CO-ORDINATION OF NATIONAL GOVERNMENT

Telegrams "DISTRICTER" Kakamega
Telephone 056 -31131
Fax 056 – 31133
Email: cckakamega12@yahoo.com
When replying please quote

COUNTY COMMISSIONER
KAKAMEGA
P O BOX 43 - 50100
KAKAMEGA.

**Ref: ED/12/1/VOL.V/161**

**Date: 22nd June, 2021**

**Ms. Rosemary Lusike Wepukhulu**
**P O Box 190 - 50100**
**KAKAMEGA**

**RE: RESEARCH AUTHORIZATION**

Following your authorization vide letter Ref: NACOSTI/P/21/11282 dated 17TH June, 2021 by NACOSTI to undertake research on ***"Clinical Management of Lymphedema Secondary to Breast Cancer Treatment by Healthcare Providers in Selected Hospitals in Western Region, Kenya"*** for the period ending 17th June, 2022.

I am pleased to inform you that you have been authorized to carry out the research on the same.

COUNTY COMMISSIONER
KAKAMEGA COUNTY

**EREDI C. M.**
**FOR: COUNTY COMMISSIONER**
**KAKAMEGA COUNTY**

**APPENDIX XIII: Letter from County Government of Bungoma**

# REPUBLIC OF KENYA

## COUNTY GOVERNMENT OF BUNGOMA
## MINISTRY OF HEALTH
## OFFICE OF THE COUNTY DIRECTOR HEALTH


**Telegrams: "MEDICAL", BUNGOMA**
**Telephone: (055) 30230 Fax: (055) 30650**
**E-mail: docakatu@yahoo.com**
**When replaying please quote**

COUNTY DIRECTOR OF HEALTH
BUNGOMA COUNTY
P. O. BOX 18 – 50200
**BUNGOMA**


**OUR REF:** CG/BGM/CDH/RESRC/VOL.1(87) **DATE:** 8TH JULY, 2021

Rosemary Lusike
Masinde Muliro University of Science and Technology
P.O. Box 190 – 50100
**Kakamega**

**RE: PERMISSION TO CARRY OUT RESEARCH IN BUNGOMA COUNTY**

Following your application for authority to carry out research in **"Clinical Management of Lymphedema Secondary to Breast Cancer Treatment by Healthcare Providers in Selected Hospitals in Western Region Kenya.",** I am pleased to inform you that you have been authorized to undertake the research for the period ending 17th June, 2022.

Kindly note that, as an applicant who has been licensed under the Science, Technology and Innovation Act, 2013 to conduct research in Kenya, you shall deposit **a copy** of the final research report to the County Director of Health. The soft copy of the same should be submitted through the online Research Information system.

Thank you.

COUNTY DIRECTOR OF HEALTH
BUNGOMA COUNTY
P. O. Box 18-50200
BUNGOMA

DR. JOHNSTON AKATU
COUNTY DIRECTOR OF HEALTH
**BUNGOMA**

**APPENDIX XIV: Letter from County Government of Kisumu**

# REPUBLIC OF KENYA

## COUNTY GOVERNMENT OF KISUMU

**Telegrams:** "PRO (MED)"
**Tel:** 254-057-2020105
**Fax:** 254-057-2023176
**E-mail:** kisumucdh@gmail.com

Director of Public Health, Preventive/
Promotion and Environmental Health
P.O. Box 721 – 40100,
**Kisumu.**

## DEPARTMENT OF HEALTH &SANITATION

**Our Ref:** GN 133 VOL.VII/(122) **Date:** 8th July, 2021

To:

**CEO – JOOTRH**

**Med Supts.- KCRH, Kombewa, Chulaimbo, Ahero, Nyakach, Muhoroni, Nyahera, Lumumba, Migosi & Rabuor**

**RE: APPROVAL TO CONDUCT RESEARCH IN KISUMU COUNTY**

The department has reviewed and approved this research titled **'Clinical Management of Lymphedema Secondary to Breast Cancer Treatment by Healthcare Providers in selected Hospitals in Western Region, Kenya'**

This principal investigator for this research activity is **Rosemary Lusike Wepukhulu**.

Kindly accord her all the necessary support.

COUNTY DIRECTOR
OF HEALTH
KISUMU

**Fredrick Oluoch**
**County Director Public Health & Sanitation**
**Kisumu County**

CC. Principal investigator Rosemary Lusike Wepukhulu

**APPENDIX VV: Approval Letter from JOOTRH Kisumu**

COUNTY GOVERNMENT OF KISUMU
DEPARTMENT OF HEALTH

**Telephone: 057-2020801/2020803/2020321**
**Fax: 057-2024337**
**E-mail:** ercjoorth@gmail.com

When replying please quote

**IERC/JOOTRH/463/21**
**Ref:** .....

**JARAMOGI OGINGA ODINGA TEACHING & REFERRAL HOSPITAL**
**P.O. BOX 849**
**KISUMU**

22nd July, 2021
**Date**.....

**To:** Rosemary Lusike Wepukhulu

Dear Rosemary,

**RE: REQUEST FOR ETHICAL APPROVAL TO UNDERTAKE A STUDY TITLED:- CLINICAL MANAGEMENT OF LYMPEDEMA SECONDARY TO BREAST CANCER TREATMENT BY HEALTH CARE PROVIDERS IN SELECTED HOSPITALS IN WESTERN REGION KENYA.**

This is to inform you that ***JOOTRH IERC*** has reviewed and approved your above research proposal. Your application approval number is ***IERC/JOOTRH/433/21.*** The approval period is ***22nd July, 2021 – 22nd July, 2022.***
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 ***JOOTRH - IERC***.
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 ***JOOTRH - IERC*** within 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 ***JOOTRH - IERC*** 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 JOOTRH - ***IERC***.

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

In case the study site is JOOTRH, kindly report to Chief Executive Officer before commencement of data collection.

Yours sincerely,

INSTITUTIONAL ETHICS & REVIEW COMMITTEE
22 JUL 2021
JOOTRH

for: SECRETARY, IERC

**APPENDIX XVI: Approval Letter from Department of Health Kisumu**

COUNTY GOVERNMENT OF KISUMU
**DEPARTMENT OF HEALTH**


Telephone: 057-2020801/2020803/2020321
Fax: 057-2024337
E-mail: medsuptnpgh@yahoo.com
ceo@jaramogireferral.go.ke
Website: www.jaramogireferral.go.ke
*When replying please quote*
GEN/21A
Ref: .....

JARAMOGI OGINGA ODINGA TEACHING &
REFERRAL HOSPITAL
P.O. BOX 849-40100
KISUMU


22nd July, 2021
Date .....

ROSEMARY LUSIKE WEPUKHULU

**RE: PERMISSION TO COLLECT DATA**

Following approval of protocol titled "Clinical management of lympedema secondary to breast cancer treatment by healthcare providers at Jaramogi Oginga Odinga Teaching and Referral Hospital – Kisumu", you are hereby permitted to proceed with the activity.

Thank you.

Yours sincerely

FOR MEDICAL SUPERINTENDENT
JARAMOGI OGINGA ODINGA TEACHING
& REFERRAL HOSPITAL (JOOTRH)
P. O. Box 849 - 40100, KISUMU.

VERA OLOO
**FOR CHIEF EXECUTIVE OFFICER**
**JOOTRH – KISUMU**

**APPENDIX XVII: Approval Letter from Medical Superintendent Siaya County**

## COUNTY GOVERNMENT OF SIAYA

## DEPARTMENT OF HEALTH AND SANITATION

E-mail: siayachd@gmail.com
ADJACENT TO JCC CHURCH
PHONE:
SIAYA TOWN

COUNTY HEALTH HEADQUARTERS
SIAYA COUNTY
P O BOX 597
SIAYA

**Our Ref: CGS/CHD/RESEARCH/VOL.IV (108)** **9TH JULY, 2021**

- Medical Superintendent
- Siaya County Referral Hospital
  SIAYA COUNTY

RE: CLEARANCE TO CONDUCT A RESEARCH ON CLINICAL MANAGEMENT OF LYMPHEDEMA SECONDARY TO BREAST CANCER TREATMENT BY HEALTHCARE PROVIDERS IN SELECTED HOSPITALS IN WESTERN REGION KENY

Rosemary Lusike Wepukhulu of Masinde Muliro University of Science and Technology has received authorization from the National Commission for Science Technology and Innovation (NACOSTI) vide License No: NACOSTI/P/21/11282 and Masinde Muliro University of Science and Technology (MMUST) Institutional Review Committee (IERC) vide MMUST/IERC/196/2021, to conduct the above referenced study in our County.

Specific Objectives

1. Assess healthcare provider's knowledge in the management of lymphedema secondary to breast cancer treatment.
2. Investigate healthcare provider's skills in the management of lymphedema secondary to breast cancer treatment.
3. Examine the strategies used in the management of lymphedema secondary to breast cancer treatment.

Data shall be collected through observation and Focus group discussion.

The study timeline runs through 22 /June 2022.

This is to notify you that the Research has been approved by the office of the undersigned, kindly accord her necessary assistance.

Thank you

Dr. Felix Tindi
County Pharmacist
SIAYA

COUNTY DIRECTOR OF HEALTH
SIAYA COUNTY
09 JUL 2021
P.O. Box 597-40600,
SIAYA.

Copy to:

- ✓ CECM –Health and Sanitation
- ✓ Ag. Chief Officer – Health and Sanitation

**APPENDIX XVIII: Approval Letter from Research Authorization from Siaya County**

REPUBLIC OF KENYA

**COUNTY GOVERNMENT OF SIAYA**
**DEPARTMENT OF HEALTH AND SANITATION**


**Telegrams: "MEDICAL, Siaya**
**Telephone: 0757955067**
**When replying please quote**

**MEDICAL SUPERINTENDANT**
**SIAYA COUNTY REFERRAL HOSPITAL**
**P .O. BOX 144 - 40600**
**SIAYA**


**Ref:** SYA/CRH/MED. SUP. COR/VI.49 **Date:** 14th July, 2021

Rosemary Lusike
**Principal Investigator**

Dear Madam

**RE: RESEARCH AUTHORIZATION**

This is to notify you that the Siaya County Referral Hospital Institution Review Committee has approved your application to conduct the study on ***"clinical management of lymphedema secondary to breast cancer treatment by healthcare providers".***

At the completion of the research, you are expected to submit a soft and hard copy of research findings to the hospital's IRC.

Thank you

SIAYA COUNTY REFERRAL HOSPITAL
MEDICAL
14 JUL 2021
SUPERINTENDENT
P.O. BOX 144-40600, SIAYA

Dr. Liech Adoyo
**MEDICAL SUPERINTENDENT**
**SIAYA COUNTY REFERRAL HOSPITAL**

***Centre of Quality Health Care***

**APPENDIX XIX: Approval Letter from Bomet County**

Relieved.
Relevant document explained.
No objection.
Dr. Kiberi

DEPUTY MEDICAL SUPERINTENDENT
LONGISA COUNTY REFERRAL
HOSPITAL
P. O. Box 34 - 20402, LONGISA
Date 16/7/2021

REPUBLIC OF KENYA

COUNTY GOVERNMENT OF BOMET

DEPARTMENT OF MEDICAL SERVICES & PUBLIC HEALTH

Director of Cancer Research & specialized Services
P.O. Box 19 - 20400
Bomet

REF: CGOB/MS/GEN.CORR. /2021

16th July, 2021

Rosemary Lusike Wepukhulu

REF: PERMISSION TO CONDUCT RESEARCH

This is to infrm you that your request to conduct a study in Bomet County titled "Clinical Management of Lymphedema Secondary to Breast Cancer Treatment by Health care providers in selected Hospital in Western Region Kenya"has been approved.

Through this letter, you are allowed to visit Bomet County facilities to collect data on the same.

While conducting your study, you are reminded to adhere to ethical considerations related to research as provided by the law and NACOSTI regulations.

I take this opportunity to wish you well as you conduct your study.

Sincerely

COUNTY GOVERNMENT OF BOMET
16 JUL 2021

Dr. Ronald Kibet (MMED, MBchB)
Director of Cancer Research & specialized Services

**APPENDIX XXX: Approval Letter from Logisa County Referral Hospital**

REPUBLIC OF KENYA

**COUNTY GOVERNMENT OF BOMET**

**DEPARTMENT OF MEDICAL SERVICES & PUBLIC HEALTH**

Director of Cancer Research & specialized Services
P.O. Box 19 - 20400
Bomet

REF: CGOB/MS/GEN.CORR. /2021 16th July, 2021

Rosemary Lusike Wepukhulu

REF: PERMISSION TO CONDUCT RESEARCH

This is to infrm you that your request to conduct a study in Bomet County titled "Clinical Management of Lymphedema Secondary to Breast Cancer Treatment by Health care providers in selected Hospital in Western Region Kenya"has been approved.

Through this letter, you are allowed to visit Bomet County facilities to collect data on the same.

While conducting your study, you are reminded to adhere to ethical considerations related to research as provided by the law and NACOSTI regulations.

I take this opportunity to wish you well as you conduct your study.

Sincerely

COUNTY GOVERNMENT OF BOMET
SERVICE & ADMINISTRATION
16 JUL 2021
Sign:
P.O. Box 19 - 20400, BOMET

Dr. Ronald Kibet (MMED, MBchB)
Director of Cancer Research & specialized Services

**APPENDIX XXXI: Western Region Map**


**Source: KDHS, 2014**